National Cancer Registrars Association

ISSN: 1945-6123

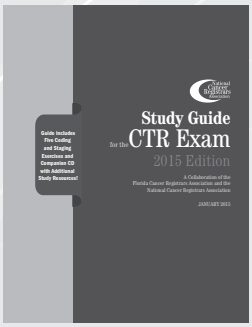
Journal of Registry Management

Summer 2015 | Volume 42 | Number 2

Published by the National Cancer Registrars Association
Founded in 1975 as *The Abstract*

NCRA: Your Source for CTR Exam Prep

NCRA Study Guide for the CTR Exam: 2015 Edition



NCRA revised its popular study guide for the 2015 exam. There are five new case studies that include answers with rationales. Companion CD contains additional study resources. NCRA member price: $85; non-member price: $105.

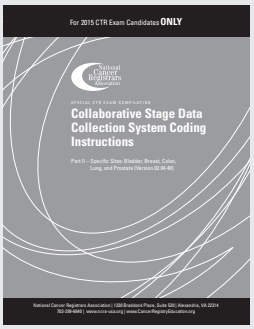
CTR Exam Prep Online Workshop

NCRA has created a CTR Exam Prep Online Workshop consisting of nine, 90-minute live webinars on critical exam topics. Workshop member price: $365; non-member price: $485: Individual webinars can be purchased separately. Member price: $45; non-member price: $60.

Sign-up for the Complete Workshop and Receive a 20% Discount on NCRA Study Guide for the CTR Exam: 2015 Edition

Special Compilation of Collaborative Stage Data Collection System Coding Instructions

(For 2015 CTR Exam Candidates Only)



NCRA has compiled the specific sites of the Collaborative Stage Data Collection System Coding Instructions to be used during the open-book portion of the exam. This easy-to-use special edition includes the five specific sites: bladder, breast, colon, lung, and prostate. NCRA member price: $50; non-member price: $75.

UPDATED FOR 2015!

NCRA's Online CTR Exam Practice Test

NCRA offers a 125-question online CTR Exam Practice Test through its Center for Cancer Registry Education (CCRE). The Practice Test is designed to provide candidates a tool to assess understanding and determine where further study is needed. Pricing options: One-time access: NCRA member - $65; non-member - $105. Unlimited access for 60 days: NCRA member - $180; non-member - $220.

ONLINE CTR EXAM PRACTICE TEST
CancerRegistryEducation.org/ctr-prep

Go to **www.ncra-usa.org/CTRPrep** to learn more and order!

Journal of Registry Management
is published quarterly by the
National Cancer Registrars Association
1330 Braddock Place, #520
Alexandria, VA 22314
(703) 299-6640
(703) 299-6620 FAX

Address change of address and subscription correspondence to:
National Cancer Registrars Association
1330 Braddock Place, #520
Alexandria, VA 22314

Address all editorial correspondence to:
Vonetta L. Williams, PhD, MPH, CTR, Editor-in-Chief
Email: JRMEditor@ncra-usa.org
Telephone: (813) 745-1783

Letters to the Editor
Letters to the Editor must be signed and include address and telephone number; none will be published anonymously. Letters subject to editing.

Editorial Policy
Opinions expressed in articles appearing in *Journal of Registry Management* are those of the authors and not necessarily those of the National Cancer Registrars Association, or the editor of *Journal of Registry Management*.

Subscription to *Journal of Registry Management*
Subscription is a benefit of membership in the National Cancer Registrars Association. Individual subscriptions may be purchased for $40/year U.S. dollars. Single copies may be purchased for $12 U.S., $15 International, prepaid only.

Advertising Sales
Advertising is accepted with the understanding that products and services are professionally related and meet the ethical standards of public health practice. Acceptance by the *Journal* does not indicate or imply endorsement by the *Journal* or NCRA. Advertising sales should be directed to
Paula Spitler, NCRA,
1330 Braddock Place, #520,
Alexandria, VA 22314,
(703) 299-6640, (703) 299-6620 FAX.

© 2015
National Cancer Registrars Association

National Cancer Registrars Association

Journal of Registry Management

Summer 2015 • Volume 42 • Number 2

Contents

Letter from the Editor-in-Chief
Vonetta L. Williams, PhD, MPH, CTR 39

Original Articles

Availability of TNM Staging Data Elements in the Medical Record and Training Needs Assessment: Results from the 2014 SEER Training Needs Assessment for TNM Study 40
Anne-Michelle Noone, MS; Nicola Schussler, BS; Serban Negoita, MD, DrPh, CTR; Margaret (Peggy) Adamo, BS, CTR; Kathleen Cronin, PhD, MPH; Jean Cyr; Donna Gress; Carmela Groves, RN, MS; Carol Kosary, DMgt; Benmei Liu, PhD; Leon Sun, PhD, CTR; Kevin Ward, PhD, CTR; Lynne Penberthy, MD, MPH

Evaluating Difficult Decisions in Public Health Surveillance: Striking the Right Balance between Timeliness and Completeness 48
Jason L. Salemi, PhD, MPH; Jean Paul Tanner, MPH; Suzanne B. Anjohrin, MPH; Rachel E. Rutkowski, MSPH; Jane A. Correia; Sharon M. Watkins, PhD; Russell S. Kirby, PhD

Renal Cancer Patients with Unknown Ethnicity in Cancer Registry Data: Comparisons to Patients with Known Ethnicity 62
Jie Lin, PhD, MPH; Elizabeth Butts, MPH, CTR; Paul D. Rockswold, MD, MPH, FAAFP; Craig D. Shriver, MD; Kangmin Zhu, MD, PhD

Features and Other Journal Departments

How the Wisconsin Cancer Reporting System's Data Quality Task Force Started a Cancer Information Management Education Program to Improve Certified Tumor Registrar Recruitment in Wisconsin 70
Mary Foote, MS

The Good, the Bad, the Ugly…and the Even Better of Rapid Abstracting 73
Karen Coyne, RN, CTR, MSc

Raising the Bar: Setting Expectations 76
Michele Webb, CTR

Summer 2015 Continuing Education Quiz 78

Call for Papers 80

Information for Authors 81

Editors
Vonetta L. Williams, PhD, MPH, CTR, Editor-in-Chief
Vicki Nelson, MPH, RHIT, CTR, Editor Emeritus
Ginger Yarger, Copy Editor
Janice Ford, Production Editor

Contributing Editors
Faith G. Davis, PhD—Epidemiology
April Fritz, BA, RHIT, CTR—Cancer Registry
Denise Harrison, BS, CTR—CE Credits
Deborah C. Roberson, MSM, CTR—CE Credits
Michele A. Webb, CTR

NCRA 2015-2016 Board of Directors
President: Leah Kiesow, MBA, CTR
President Elect/Secretary: Linda Corrigan, MHE, RHIT, CTR
Immediate Past President: Terri M. Richardson, RHIA, CTR
Treasurer Senior: Kathleen Hess, RHIT, CTR
Treasurer Junior: Dana Lloyd, MS, RHIA, CTR
Educational Director: Paulette Zinkann, CTR
Professional Development Director: Sharmen Dye, CTR
Public Relations Director: Kyle L. Ziegler, CTR
Recruitment & Retention Director: Janet Reynolds, CTR
ATP Director—East: Jayne Holubowsky, CTR
ATP Director—Midwest: Maria Teresa Ramirez, BS, CTR
ATP Director—West: Tiffany Jane, CTR

NCRA Staff
Janice Ford, Membership Manager
Peggy Meehan, Director, Education and Communications

2014-2015 *JRM* Editorial Advisory Board
Boazhen Qiao, MD, PhD
Beibei Lu, PhD
Roneé E. Wilson, PhD, MPH
Tammy Berryhill, MA, RHIA
Monique Hernandez, PhD
Donna Gress. CTR
Alison Hennig, BS, CTR
Amy Kahn, MS, CTR
Pamela Webster, PhD, CTR
Mary O'Neil, MPH
Selina Radlein, MPH
Pamela Warren, PhD, CTR
Herman Menck, MBA, CDP (Editor Emeritus)
Vicki Nelson, MPH, RHIT, CTR (Editor Emeritus)
Jody Plantz, BS, CTR (Associate Editor)

Production and Printing
The Goetz Printing Company

Indexing

The *Journal of Registry Management* is indexed in the National Library of Medicine's MEDLINE database. Citations from the articles indexed, the indexing terms (key words), and the English abstract printed in *JRM* are included and searchable using PubMed.

For your convenience, the *Journal of Registry Management* is indexed in the 4th issue of each year and on the Web (under "Resources" at **http://www.ncra-usa.org/jrm**). The 4th issue indexes all articles for that particular year. The Web index is a cumulative index of all *JRM* articles ever published.

Letter from the Editor

Vonetta L. Williams, PhD, MPH, CTR

Editor-in-Chief, Journal of Registry Management

Greetings! It is both a blessing and an honor to be the new editor-in-chief of the *Journal of Registry Management (JRM*). I extend a heartfelt thank you to our editor emeritus, Vicki Nelson, MPH, RHIT, CTR, for all of her hard work and dedication to the National Cancer Registrars Association (NCRA) and *JRM*. In addition, we would like to take this opportunity to welcome our new associate editor, Jody Plantz, CTR, to the *JRM* team. Jody is a cancer registrar at the University of Colorado Health in Fort Collins, Colorado.

I am a recent graduate of the University of South Florida, with my PhD in public health. I am currently the manager of Information Shared Services at Moffitt Cancer Center and Research Institute in Tampa, Florida. I have spent the last 4 years serving as the associate editor of *JRM* and I'm excited about this new role and working to achieve our strategic priorities.

We reviewed the results from the *JRM* readership survey and we hear you loud and clear. Based on your feedback, we have been implementing various strategic priorities to make *JRM* relevant to the daily professional life of a registrar. In this issue of *JRM,* we have Karen Coyne, RN, CTR, MSc, who graciously agreed to share the process her team is currently utilizing with rapid abstracting in the article, "The Good, the Bad, the Ugly…and the Even Better of Rapid Abstracting". Karen presented this information at our National Cancer Registrars Association Annual Meeting in May 2015, and many of you had questions and requested additional information. Another article included in this summer issue, entitled "How the Wisconsin Cancer Reporting System's Data Quality Task Force Started a Cancer Information Management Education Program to Improve Certified Tumor Registrar Recruitment in Wisconsin" from Mary Foote, MS, and her team is applicable to all of us in addressing the current shortage of certified tumor registrars (CTRs).

In addition to the "How I (We) Do It" articles, Michele Webb, CTR, details the importance of customer service and provides 3 important steps for setting expectations with our customers. Lastly, there are original manuscripts from Dr. Jin Lin and colleagues comparing renal cancer patients with known and unknown ethnicity, Anne-Michelle Noone, MS, and team assessing the availability of TNM staging variables in the patient medical record, and Dr. Jason L. Salemi and team evaluating timeliness and completeness of data collected from the Florida Birth Defects Registry.

We hope you enjoy reading this summer issue of *JRM* and we welcome any feedback you may have. Please contact us at the following email address, JRMeditor@NCRA-USA.org.

Respectfully,

Vonetta L. Williams, PhD, MPH, CTR
Editor-in-Chief, *Journal of Registry Management*
National Cancer Registrars Association

Original Article

Availability of TNM Staging Data Elements in the Medical Record and Training Needs Assessment: Results from the 2014 SEER Training Needs Assessment for TNM Study

Anne-Michelle Noone, MS[a]; Nicola Schussler, BS[b]; Serban Negoita, MD, DrPh, CTR[c]; Margaret (Peggy) Adamo, BS, CTR[a]; Kathleen Cronin, PhD, MPH[a]; Jean Cyr[b]; Donna Gress[d]; Carmela Groves, RN, MS[c]; Carol Kosary, DMgt[a]; Benmei Liu, PhD[a]; Leon Sun, PhD, CTR[a]; Kevin Ward, PhD, CTR[e]; Lynne Penberthy, MD, MPH[a]

Abstract: Background: In 2016, the cancer registry community will directly assign T, N and M components of stage. The Surveillance, Epidemiology, and End Results program implemented a field study to determine how often T, N and M were not available in the medical record, requiring the registrar to directly assign clinical or pathologic TNM stage components. The field study also identified specific training needs. Methods: T, N and M status were collected from multiple sources within medical records for a total of 280 cases, 56 each from breast, prostate, colon, lung, and ovarian cancer. TNM data elements were also directly assigned by a series of reviewers and by study participants using the medical records with TNM information redacted. Availability of physician-assigned TNM was estimated from the medical record. Also, participant responses were compared to preferred answers. Results: Pathologic T, N and M were available more often in the medical records than were clinical values and varied by site. Pathologic T and N were available for about two-thirds of the cases, but the clinical elements were available for only about 20% of cases. The agreement between participant responses and review panel assignments varied by data element and cancer site. Agreement was modest for most data elements and cancer sites, ranging from 54% for clinical T to 92% for clinical M for all cancer sites combined. Conclusions: The data elements for TNM staging and stage group were often missing from the medical records, so registrars in the field will need to assign TNM frequently. Furthermore, the results of this study strongly suggest that more training is required, even among those who currently assign TNM.

Key words: *AJCC TNM, cancer staging, data quality, training*

Background

Staging describes the extent of an individual's cancer at the time of diagnosis and plays a vital role in managing patient care. The American Joint Committee on Cancer (AJCC) leads the effort in the United States to develop a standardized staging system and collaborates with the Union for International Cancer Control (UICC) to maintain a system that is used worldwide. Traditionally, staging represented anatomic information on the extent of disease and summarized information into 3 categories: the size of the tumor and the extent that the tumor has invaded nearby tissue (T), whether the cancer has spread to nearby lymph nodes (N), and whether the cancer has metastasized to other parts of the body (M). Together T, N and M form the basis for cancer staging. Since 2004 cancer registries collected information within the Collaborative Stage Data Collection System (CS) which consisted of a set of building blocks that were developed to provide the foundation needed to translate the extent of disease information into multiple staging systems including the AJCC Staging System based on T, N, and M.

In 2016, the cancer registry community will directly assign T, N and M components of stage and will no longer use the CS system for deriving the AJCC Staging System. Since preliminary studies conducted by the National Cancer Registrars Association (NCRA) and Commission on Cancer (CoC) indicated that cancer registrars may need additional training to accurately assign cancer stage using the TNM system,[1,2] the Surveillance, Epidemiology, and End Results (SEER) program at the National Cancer Institute conducted a field study for cancer registrars. The objectives were to determine how often T, N, and M were assigned by medical practitioners and available in the medical record (MR). In addition, this study assessed the training needs of tumor registrars that are required to directly assign either clinical or pathologic TNM stage components. The results will also provide a baseline to evaluate the effectiveness of future training materials among cancer registrars in CoC-accredited facilities, non–CoC-accredited facilities, and central registries.

[a]Division of Cancer Control and Populations Sciences, National Cancer Institute, Bethesda, Maryland. [b]Information Management Services, Inc, Calverton, Maryland. [c]Westat, Rockville, Maryland. [d]American Joint Committee on Cancer, American College of Surgeons, Chicago, Illinois. [e]Emory University, Atlanta, Georgia.

Address correspondence to Anne-Michelle Noone, National Cancer Institute, Division of Cancer Control and Population Sciences, Surveillance Research Program, 9609 Medical Center Drive, Rockville, MD 20850. Telephone: (240) 276-6705. Email: noonea@mail.nih.gov.

Methods

Selection of Cases

Copies of de-identified MRs for 50 routine cancer cases diagnosed in 2013 were requested from each of 14 SEER registries, 10 of which submitted cases in time for inclusion into the study. To assure representativeness of the typical caseload of a registry, the registries generally followed a sequential sampling scheme when selecting records. All available components of the MR were sent, including, but not limited to, consultation notes, discharge summaries, imaging, pathology, and operative reports. Each registry was asked to submit 5 cases from a CoC-accredited facility and 5 from a non–CoC-accredited facility for each of 5 cancer sites (female breast, prostate, colon, lung, and ovary), for a goal of 700 submitted MRs. The cases included in this study were selected from this set. Cases from each registry were included and cases were selected on a rolling basis as they were submitted. About 75% of the study cases came from 6 registries (about 10%–11% of cases each) and the remaining cases came from 4 registries (about 4.5% of cases each).

In order to detect a 95% agreement between a participant-assigned data element (eg, T, N, or M) and the preferred answers within a ± 5% margin of error, a sample size of 73 cases per cancer site would be required. With 56 cancer cases, the margin of error is 5.7%. An alternative calculation based on the sample size required to obtain a kappa statistic of 90%, which took into account the expected stage distribution, indicated that 64 to 83 cases would be required to obtain a ± 8% margin of error. A final sample size of 56 cancer cases per site, 280 total, was selected after balancing the precision and the resources required to prepare each case for the study.

As part of the MR preparation, we first reviewed the 280 study records to ensure no patients had multiple reportable primary tumors and that the combination of primary site and histology was valid for AJCC staging. Two additional practice cases were also selected so that participants could practice using the study software before beginning the study cases. Second, we removed all confidential information as well as all AJCC staging components that have been directly assigned by a medical provider including the AJCC stage group when available. Stage and stage-related data elements were removed by blacking out the text in the MRs; the resulting records will henceforth be referred to as the redacted medical records (RMR). Appendix A shows data elements that were redacted for 280 MRs used in the study and 2 practice MRs selected for this study. The redacted information was stored in a database for analysis, but was not presented to participants or reviewers. The information was withheld in order to simulate the field situation in which the medical provider–assigned T, N, M and stage group is not available and therefore the registrar would need to assign T, N and M. The 280 study RMRs were arbitrarily divided into 28 groups. Each group contained 2 RMRs for each cancer site: 1 from a CoC- accredited facility and 1 from a non–CoC-accredited facility, for a total of 10 study RMRs.

Study Participation

An invitation to participate in the study was sent electronically to all SEER and National Program of Cancer Registries (NPCR) registries and advertised by the North American Association of Central Cancer Registries (NAACCR). All cancer registrars in the United States and Canada were eligible to participate in the study, which was open from July 7 to August 22, 2014. The invitation included the uniform resource locator (URL; Web address) for the SEER Reliability website, which was used for this study. All study participants created an online account for the SEER Reliability website using a unique username and password. After providing selected demographic information, participants were offered 2 practice RMRs to become familiar with the study software. Then the participants were randomly assigned to 1 of the 28 groups of 10 RMRs, for which they reviewed the RMRs and were asked to assign all stage-related data elements (Appendix A). SEER Summary Stage 2000 (SS2000) was also collected, since there may be situations where algorithmically deriving TNM stage is not possible, thus requiring direct assignment of stage. RMR for each case was available for viewing as a PDF document. While participants were completing the study, they were permitted and encouraged to use available standard resources that would assist them in assigning the data elements.

Once the participant had been assigned a group of 10 cases, 2 cases per site, the participant could complete data entry for the cases in any order. Participants recorded their responses using drop-down menus for each data element and could choose from the allowed responses shown in Appendix B. After completing 10 cases, the participant could request a second set of 10 cases. All completed cases were included in the analysis, so each participant contributed data for at least 1 and up to 20 cases. Partially completed cases were discarded and not included in the analysis. As an incentive to participate, NCRA continuing education units were available to participants who completed 1 or 2 complete sets of cases.

Determination of the Preferred Answer

Two experienced registrars reviewed each RMR and independently assigned all data elements. If the first 2 reviewers disagreed, a third reviewer adjudicated their responses. Only 10% of the 2,709 data elements required adjudication because of disagreement between reviewers. The most challenging data element, requiring the most adjudication, was clinical T (20.6%), followed by AJCC clinical stage group (15.3%). The adjudicated responses for all staging data elements were used as the preferred answer for analysis.

Data Analysis

First, the availability of physician-assigned staging elements as documented in the MR was determined from the redacted information. In addition, the proportion of records with conflicting values for the same data element was examined. This information provides insight into how often the registrars will have to independently assign or, in

some cases, verify, T, N and M in the field.

For the purpose of analyzing the agreement of participant responses with the preferred answer, we combined all responses for cases from each cancer site (56 cases per site). Next we excluded responses for certain cases that were ineligible for clinical or pathologic staging. We identified 1 colon case ineligible for clinical T, 1 ovary case ineligible for clinical M, and 66 cases ineligible for pathologic T, N and M (5 breast, 3 colon, 7 ovary, 29 lung, and 22 prostate). All cases were eligible and therefore included in the analysis of agreement for SEER Summary Stage 2000 (SS2000). Agreement with the preferred answer was assessed in 2 ways. The first was to assess the agreement with the preferred answer for each variable for a specific cancer site across all cases within the study. For this assessment, agreement was measured at a detailed level of TNM staging, including substages (eg, T1a, T1b, etc). A sensitivity analysis was performed using collapsed stage elements in order to adjust for minor discrepancies. The collapsed groups were formed by combining categories into logical groups that result in the same stage group (Appendix B). Since participants who regularly assign TNM may have higher agreement with the preferred answers, this analysis was stratified by participants who responded positively to the demographic question, "Do you regularly assign TNM as part of your work?" and those who did not.

A further analysis was performed to assess consistency in participant coding of each data element. For each site and data element, we counted the number of cases for which the data element was assigned in agreement with the preferred answer by at least 85% of participants. A threshold of 85% agreement has been used in previous SEER data quality studies as an acceptable level of consistency. Then we calculated the percentage of cases in which the study participants consistently assigned each data element.

Table 1. Demographic and Experiential Characteristics of Participants (N = 843)

	n	%
Location of Registrar		
CoC-accredited facility	461	54.7
Non–CoC-accredited facility	105	12.5
Central registry	277	32.9
Number of Cases Abstracted per Year		
≤250	230	27.3
251–500	220	26.1
>500	318	37.7
Unknown	75	8.9
Years of Experience Abstracting		
Mean (Range)	11.5 (0-42)	
Reported Regularly Assigning TNM Stage		
Yes	563	66.8
No	274	32.5
Unknown	6	0.7
Recently Completed Some TNM Training		
Yes	146	17.3
No	691	82.0
Unknown	6	0.7

Results

Demographic Characteristics

Table 1 provides the characteristics of the 843 study participants. Most of the 843 participants were registrars in CoC-accredited facilities, and 38% of participants abstracted 500 or more cases per year. On average, participants had 11.5 years of experience, with a range from 0 years (30 registrars) to 42 years (1 registrar). Over two-thirds (68%) reported having 6 or more years of experience. Sixty-seven percent reported that they regularly assigned TNM as part of their work, and 17% reported having had some training in TNM staging in the previous 6 months, although the type of training was not specified.

Table 2. Percentage of Medical Records that Contained Each Data Element

	Breast	*Colon*	*Lung*	*Ovary*	*Prostate*	*Total*
Clinical T	21	5	32	2	53	23
Clinical N	21	5	32	2	33	19
Clinical M	16	5	32	2	35	18
Pathologic T	88	88	36	61	56	66
Pathologic N	86	86	36	59	56	65
Pathologic M	63	63	16	27	32	40
AJCC Group Path Stage	42	57	13	63	16	38
AJCC Group Clin Stage	23	11	46	30	19	26

AJCC, American Joint Committee on Cancer. There were 57 cases of breast and prostate and 56 for colon, lung and ovary included in order to show availability of data. However, there were cases included ineligible for staging (clinical T, 1 colon case; clinical M, 1 ovary case; pathologic T, N, M, 5 breast cases, 3 colon cases, 7 ovary cases, 22 prostate cases, 29 lung cases).
There were 282 cases total.

Table 3. Percentage of All Responses that Agreed with the Preferred Answer at the Detailed Level of TNM Staging by Cancer Site among All Participants, Those Who Reported Regularly Assigning TNM (Reg Assign), and Those Who Did Not (Not Reg Assign)*

	Breast			*Colon*			*Lung*			*Ovary*			*Prostate*		
Detailed Categories of T, N, M†	All	Reg Assign	Not Reg Assign	All	Reg Assign	Not Reg Assign	All	Reg Assign	Not Reg Assign	All	Reg Assign	Not Reg Assign	All	Reg Assign	Not Reg Assign
Clinical T	59	61	54	60	60	58	60	60	59	27	28	26	64	66	59
Clinical N	76	77	71	52	52	51	72	71	73	55	56	55	79	82	75
Clinical M	98	98	99	91	91	91	87	88	85	87	87	87	96	95	97
Pathologic T	77	78	74	76	76	76	72	74	70	47	48	46	70	70	68
Pathologic N	69	67	71	84	86	81	83	85	81	80	80	78	84	84	85
Pathologic M	99	99	99	85	86	83	88	89	86	81	81	80	99	99	99
SS2000	89	90	88	67	67	65	76	76	76	59	60	58	84	83	84

SS2000, SEER Summary Stage 2000.

*See Appendix A, Data Elements Removed from the Medical Records and Assigned by Participants.

†See Appendix B for allowed categories.

The number of responses for each data element for all, regularly assign, and do not regularly assign are given in parentheses:

Breast SS2000, clinical T, N, M (1802, 1236, 566), pathologic T, N, M (1652, 1136, 516); Colon clinical T (1657, 1121, 536), SS2000, clinical N,M (1677, 1136, 541), pathologic T, N, M (1586, 1070, 516); Lung SS2000, clinical T, N, M (1699, 1158, 541), pathologic T, N, M (827, 570, 257);

Ovary SS2000, clinical T, N (1648, 1113, 535), clinical M (1615, 1095, 520), pathologic T, N, M (1437, 970, 467); Prostate SS2000, clinical T, N, M (1742, 1193, 549), pathologic T, N, M (1079, 740, 339). The number of responses is greater than the number of participants since each participant completed more than 1 case.

Availability of TNM and Stage Group in the Medical Record

For all cancer sites combined, clinical stage group was available in 26% of MRs (Table 2). It was available least often for colon cancer, in 11% of cases, and most often for lung, in 46% of cases. Pathologic stage group was available more often, but was still only available for 38% of all cases combined, ranging from 13% for lung to 63% for ovary cases. Availability of both clinical and pathologic T, N, M values varied by cancer site and were generally available more often for pathologic data elements. Finally, between 6% and 25% of cases had multiple occurrences of a single data element with different values in the MR (results not shown). This occurred for about one-fourth of the cases for clinical T and AJCC pathologic stage group and for about 6% of the cases for clinical M.

Agreement between Participant Responses and Preferred Answers

Table 3 provides the results of the participant responses for T, N, M and SS2000 by cancer site for the detailed categories of T, N, and M. Both by staging element and by cancer site, for all participants combined, there was a wide range in the percentage of responses that agreed with the preferred answer. In general, the assignment of both clinical and pathologic M had the highest agreement, at 81% or more for all cancer sites. Pathologic N also had generally high agreement, although agreement ranged from 69% for breast to 84% for colon and prostate. SS2000 had relatively low agreement for colon, lung, and ovary (range, 59%–76%), but slightly higher agreement for prostate (84%) and breast (89%).

In order to adjust for minor discrepancies, we collapsed some of the detailed data element values to represent logical combinations that would not change the stage group of the case (Table 4). The increase in agreement as measured by percentage points varied by cancer site. For ovary, no values were collapsed because any collapse would affect the stage group; hence, there was no change in agreement for any of the staging elements. For breast, there was substantial improvement in agreement based on the collapse: 12 percentage points for pathologic T, 17 for clinical T, and 21 for pathologic N. For colon, only N was collapsed that resulted in a 2 percentage point increase for clinical N. Lung had improvement for pathologic T and M (4 and 2 percentage point improvements, respectively), as well as for clinical T and clinical M (4 and 5 percentage point improvements, respectively). Finally, prostate had some improvement, with percentage point increases ranging from 7 percentage points for pathologic T to 2–3 for clinical T and M.

In addition to the overall analysis, we stratified by those who reported regularly assigning TNM. These results are provided in Tables 3 and 4. For most data elements, registrars who regularly assigned TNM had slightly higher agreement with the preferred answers than those who did not regularly assign TNM. However, the agreement scores for the experienced participants were less than 6 percentage points higher for all data elements except clinical T for breast (8 percentage points), and clinical T and N for prostate (7 percentage points).

Cases with High Level of Consistency

As part of the analysis of the study cases, we assessed

Table 4. Percentage of All Responses that Agreed with the Preferred Answer at the Collapsed Level of TNM Staging by Cancer Site Among All Participants, Those Who Reported Regularly Assigning TNM (Reg Assign), and Those Who Did Not (Not Reg Assign)*

	Breast			*Colon*			*Lung*			*Ovary*			*Prostate*		
Collapsed Categories of T, N, M†	All	Reg Assign	Not Reg Assign	All	Reg Assign	Not Reg Assign	All	Reg Assign	Not Reg Assign	All	Reg Assign	Not Reg Assign	All	Reg Assign	Not Reg Assign
Clinical T	76	77	74	60	60	58	64	64	64	27	28	26	65	67	62
Clinical N	76	78	72	54	54	53	72	71	73	55	56	55	79	82	75
Clinical M	98	98	99	91	91	91	92	92	91	87	87	87	99	99	99
Pathologic T	89	88	90	76	76	76	76	76	75	47	48	46	77	76	78
Pathologic N	90	90	90	84	92	90	83	85	81	80	80	78	84	84	85
Pathologic M	99	99	99	85	86	83	90	90	89	81	81	80	99	99	99

SS2000: Surveillance, Epidemiology, and End Results (SEER) Summary Stage 2000

*See Appendix A, Data Elements Removed from the Medical Records and Assigned by Participants.

†See Appendix B for allowed categories.

The number of responses for each data element for all, regularly assign and do not regularly assign are given in parentheses:

Breast SS2000, clinical T, N, M (1802, 1236, 566), pathologic T, N, M (1652, 1136, 516); Colon clinical T (1657, 1121, 536), SS2000, clinical N,M (1677, 1136, 541), pathologic T, N, M (1586, 1070, 516); Lung SS2000, clinical T, N, M (1699, 1158, 541), pathologic T, N, M (827, 570, 257); Ovary SS2000, clinical T, N (1648, 1113, 535), clinical M (1615, 1095, 520), pathologic T, N, M (1437, 970, 467); Prostate SS2000, clinical T, N, M (1742, 1193, 549), pathologic T, N, M (1079, 740, 339). The number of responses is greater than the number of participants since each participant completed more than 1 case.

the percentage of cases for which the registrars had high consistency with the preferred answer. Table 5 provides the percentage of cases where participants agreed with the preferred answer more than 85% of the time. Overall, the percentage of cases for which the participants had high consistency was small. Consistency was higher for the pathologic staging elements than for clinical elements, but varied widely by cancer site. The results for SS2000 also varied by cancer site. Assignment of SS2000 was consistent for 75% of breast cases but only 11% of ovarian cases.

Overall, there were more cases with consistently assigned data elements among those who regularly assign TNM than among those who do not (Table 5). However, the results show an inconsistency in TNM staging. For example, despite higher percentages among those who regularly assign TNM, only 13% of breast cases were assigned consistently for clinical T and 45% for pathologic T overall. Results for ovary were low among those who regularly assigned TNM, despite slightly better consistency than among those who do not regularly assign.

Discussion

This study aimed to estimate how often the individual TNM staging elements were found in the MR, which reveals how often the registrar would be required to independently assign TNM data elements or stage group. A second objective was to assess the agreement between participant responses and preferred answers for a variety of cases, providing quantitative data on the extent of training needed for registrars to directly assign TNM data elements starting in 2016. With respect to the first aim, the results indicate that for a wide variety of cases, physician-assigned stage was not often available from the MRs. Even when it was available, it was frequently in conflict with other information in the MR, requiring registrars in the field to either directly assign or adjudicate information found in the MRs.

With respect to the second aim, this study used de-identified MRs from hospital facilities to provide cases that were representative of what a typical hospital registrar would have available for abstracting. While the difficulty of assigning T, N and M varied among the study cases, there were few cases across cancer sites for which the participants were able to correctly assign all of the TNM staging elements. The results show that registrars require significant training to accurately assign the data elements for TNM staging for all cancer sites. In particular, the results for ovary were poor, which was most likely due to a lack of understanding of the anatomy of the abdominal cavity. Training could potentially improve the quality of staging for this site. Furthermore, accurate assignment of each data element is critical in order to algorithmically derive the TNM stage group. Finally, there may be situations where algorithmically deriving TNM stage is not possible, thus requiring direct assignment of stage, such as SS2000. The results of this study show that direct assignment of SS2000 was moderate to poor depending on the cancer site, which may be because SS2000 was derived algorithmically in CS and therefore registrars are not practiced in directly assigning it.

This study's results raise concerns about the future quality of staging data if adequate training and evaluation of training effectiveness are not performed before moving to TNM staging. Two other studies are consistent with the findings reported here. The first study assessed the perceived

Table 5. Percentage of Cases by Cancer Site where Participants had a High (≥85%) Agreement with the Preferred Answers*

	Breast			*Colon*			*Lung*			*Ovary*			*Prostate*		
	All	Reg Assign	Not Reg Assign	All	Reg Assign	Not Reg Assign	All	Reg Assign	Not Reg Assign	All	Reg Assign	Not Reg Assign	All	Reg Assign	Not Reg Assign
Clinical T	13	29	18	6	13	18	25	23	25	2	0	2	25	39	18
Clinical N	50	57	43	16	23	13	36	38	36	7	14	14	63	71	36
Clinical M	96	96	98	79	80	80	61	66	66	67	71	66	91	91	91
Pathologic T	45	57	35	55	51	59	52	67	37	4	6	8	32	29	38
Pathologic N	26	24	39	59	62	60	60	74	56	53	53	55	68	71	68
Pathologic M	98	98	98	77	76	74	74	78	78	51	57	53	97	97	97
SS2000	75	80	68	41	39	41	52	54	46	11	13	18	64	66	64

*See Appendix A, Data Elements Removed from the Medical Records and Assigned by Participants.

availability of TNM staging by SEER registrars.[3] A total of 148 registrars responded to a questionnaire asking about the availability of physician-assigned TNM in medical records. Most of the respondents worked in CoC-accredited hospitals or central registries. About one-third of respondents reported that clinical TNM was available often or always, and 65% reported that pathologic TNM was available often or always.

A second study was performed using the National Cancer Data Base (NCDB), which consists of hospital registry data collected in more than 1,500 CoC-accredited facilities.[2] The NCDB includes clinical and pathologic TNM, along with information about who assigned the stage variable for a case. Clinical TNM values were compared with derived CS values, where the CS evaluation fields showed that the staging was based on clinical information for breast, lung, colorectal, and prostate cancers. Similarly, pathologic TNM was compared with CS values based on pathology. Agreement between directly assigned T and CS- derived T was better than the agreement with the preferred answers in this study (range: 75% to 92% for pathologic and 68% to 79% for clinical) but worse for N (68% to 88% for pathologic 50% to 78% for clinical) and M (70% to 92% for clinical). It is important to note that there are differences between how TNM is assigned and how the CS algorithm works, and these dissimilarities can lead to differences between derived and assigned TNM. CS is a "best stage" system and uses all available information, whereas TNM distinguishes between clinical (based on information before surgery) and pathologic information (obtained from surgical treatment).[4] Given the difference in approach between CS and TNM, the results of the NCDB analysis are quite consistent with the results presented here.

The TNM training needs assessment reported here has several strengths. First, a large number and variety of cases were included. The requested cases and sampling procedure provided a representative sample of the typical caseload in the field, not just difficult or rare cases. Furthermore, there was only 1 data element of 1 case for which the reviewers could not agree on the preferred answer. The high agreement among the reviewers suggests that the cases were not particularly unusual or difficult. In addition, each case was staged on average by at least 30 participants, most of whom were experienced registrars. A weakness of the study is that although all parts of the MRs available at the facility were submitted for use in this study, it is possible that some reports were not available if the case was not complete. However, even if some parts of the MR were missing, the cases used in the study represent what would have been available to the registrar at that facility in the field at the time of assigning stage. A second weakness is that, like other data quality studies conducted in the field, a volunteer sample of participants, as opposed to a probability-based sample, was used to save time and cost. Finally, after adjudication by the review panel, the preferred answers were considered fixed. Future analyses are planned to evaluate the agreement between physician-assigned T, N, M and the preferred answer which may provide insight into how consistent TNM assignment is and highlight future training needs.

In conclusion, this study corroborates previous findings that indicate the need for significant training before transitioning to TNM staging. The data elements for TNM staging and stage group were often missing from the MRs, so registrars in the field will need to assign TNM frequently. Moreover, the results of this study strongly suggest that the need for more training is not limited to registrars without extensive prior experience in assigning TNM, but rather is important even among those who currently assign TNM. This study raises significant concerns about the ability to maintain high quality of staging data in cancer registries. Thus careful consideration and planning will be needed as we transition to TNM staging, both to adhere to the timeline and to assure that training is effective. Future studies will be conducted to evaluate the effectiveness of training materials and the impact that this change to the TNM system will have on trends over time.

Acknowledgements

We would like to express our gratitude to the members of the expert panel, who worked together to determine the preferred answers for the redacted records. We would also like to express our thanks to everyone who participated in the study. We hope that our collective efforts will ensure that our field staff have sufficient training to carry out the data collection work we ask of them. Finally, we thank the registries for sending us their study cases.

References

1. National Cancer Registrars Association. Educational needs assessment: preparing for direct coding of the AJCC TNM staging. Expert panel meeting. January 31, 2014.
2. National Cancer Institute, Commission on Cancer, American Cancer Society. Comparison of Directly Assigned TNM and CS Derived TNM in NCDB database (NCI, CoC, ACS Update). *Collaborative Stage Transition Newsletter.* October 17, 2014.
3. National Cancer Institute Surveillance Epidemiology and End Results Program. Perceived Availability of Clinical and Pathologic TNM. 2012. Unpublished report.
4. Commission on Cancer. *Facility Oncology Registry Data Standards: Revised for 2015*. Chicago, IL: American College of Surgeons; 2015.

Appendix A. Data Elements Removed* from the Medical Records and Assigned by Participants

Data Element	*NAACCR Item Number*
Pathologic T	880
Pathologic N	890
Pathologic M	900
Clinical T	940
Clinical N	950
Clinical M	960
AJCC 7th Clinical Stage Group	970
AJCC 7th Pathologic Stage Group	910
SEER Summary Stage 2000	759
PSA (prostate only)*	2880 (SSF 1)
Clinical Gleason (prostate only)*	2862 (SSF 8)
Pathologic Gleason (prostate only)*	2864 (SSF 10)

AJCC, American Joint Committee on Cancer; NAACCR, North American Association of Central Cancer Registries; PSA, prostate-specific antigen; SEER, Surveillance, Epidemiology, and End Results program. *PSA and Gleason data were not redacted from the Medical Records.

Order Today!

NCRA 2015
Encore Session DVD

Watch your favorite presentation again or share it with a co-worker who was unable to attend. DVD contains high-quality video and audio. CE credits can be earned by completing the viewing form on the DVD. To order, go to ***www.ncra-usa.org/2015DVD****.*

Appendix B. Allowed Responses and How They Were Collapsed for the Sensitivity Analysis by Site*									
	Breast		*Colon*		*Lung*		*Ovary*	*Prostate*	
	Detailed	Grouped	Detailed	Grouped	Detailed	Grouped		Detailed	Grouped
T	TX	TX	TX	Tx	TX	TX	TX	TX	TX
	T0	T0	T0	T0	T0	T0	T0	T0	T0
	Tis	Tis	Tis	Tis	Tis	Tis	T1	T1	T1
	Tis (DCIS)		T1	T1	T1	T1	T1a	T1a	
	Tis (LCIS)		T2	T2	T1a		T1b	T1b	
	Tis (Paget's)		T3	T3	T1b		T1c	T1c	
	T1	T1	T4a	T4a	T2	T2	T2	T2	T2
	T1mi		T4b	T4b	T2a	T2a	T2a	T2a	T2a
	T1a				T2b	T2b	T2b	T2b	T2b
	T1b				T3	T3	T2c	T2c	T2c
	T1c				T4	T4	T3	T3	T3
	T2	T2					T3a	T3a	
	T3	T3					T3b	T3b	
	T4	T4					T3c	T4	T4
	T4a								
	T4b								
	T4c								
	T4d								
N	NX	NX	NX	NX	NX	NX	NX	NX	NX
	N0	N0	N0	N0	N0	N0	N0	N0	N0
	N1	N1	N1	N1	N1	N1	N1	N1	N1
	N2	N2	N1a		N2	N2			
	N2a		N1b		N3	N3			
	N2b		N1c						
	N3	N3	N2	N2					
	N3a		N2a	N2a					
	N3b		N2b	N2b					
	N3c								
M	M0	M0 clinical only	M0	M0	M0	M0	M0	M0	M0
	M0(i+)		M1	M1	M1	M1	M1	M1	M1
	M1	M1	M1a	M1a	M1a			M1a	
			M1b	M1b	M1b			M1b	
								M1c	

*Note that blank was not an allowed response and some data elements could not be collapsed.

Original Article

Evaluating Difficult Decisions in Public Health Surveillance: Striking the Right Balance between Timeliness and Completeness

Jason L. Salemi, PhD, MPH[a,b]; Jean Paul Tanner, MPH[b]; Suzanne B. Anjohrin, MPH[c]; Rachel E. Rutkowski, MSPH[b]; Jane A. Correia[c]; Sharon M. Watkins, PhD[c]; Russell S. Kirby, PhD[b]

Abstract: Introduction: State-based surveillance programs play a key role in birth defects planning, prevention, education, support, and research activities. High-quality data are essential to all of these functions, and a key indicator of quality is timeliness. The Florida Birth Defects Registry (FBDR)—one of the largest population-based state registries in the United States—faces challenges with timeliness, as evidenced by its 18-month lag time. The goal of this study was to determine if the timeliness of the FBDR could be improved without significantly reducing the completeness of birth defect ascertainment. Methods: Using 2006–2011 data from the FBDR, we first investigated the timing of diagnosis of birth defects by estimating the effect of different periods of follow-up on prevalence rates reported by the FBDR. We achieved this through retrospective reconstructions of the FBDR under 5 different scenarios with progressively narrower follow-up windows for each infant, and by comparing recalculated rates to the rate of the current FBDR with 1 year of follow-up. We then considered scenarios in which the time lag used to construct the FBDR was reduced (15, 12, 9, and 6 months) by using less data (from 7 to 4 quarters). Recalculated rates were again compared to the current FBDR constructed with 2 years of data and an 18-month lag. Analyses were performed overall and for 44 specific defects. Results: During the 6-year study period, the FBDR identified more than 27,000 infants with a defect detected during the first year of life. Restricting follow-up from 1 year to 9 months would only result in a loss of 1.4% of cases. Cutting follow-up in half to 6 months would miss 3.2% of cases, although there was significant variation across defects. Improving timeliness had a small impact on completeness of ascertainment. Overall, compiling the FBDR with only 6 quarters of Florida Agency for Health Care Administration data (as opposed to 8 quarters) would improve timeliness by approximately 6 months, resulting in a registry that is 99.4% complete. Discussion: Six-to-nine month improvements in timeliness were achievable with a minimal sacrifice in completeness (0.6%–1.7%). Efforts to enhance data quality through the assessment of timeliness and completeness indicators are not unique to birth defects surveillance programs. Other programs, particularly those with similar passive case ascertainment protocols, can use our findings to consider a more timely release of registry data, or to design similar investigations of their own.

Key words: *birth defects, completeness, quality, surveillance, timeliness*

Introduction

In the United States, an infant is born with a birth defect every 4 and a half minutes, which translates into nearly 120,000 affected infants each year.[1] Birth defects impact every body system, are collectively the leading cause of infant mortality in the United States, and contribute substantially to long-term morbidity.[2,3] Through the acquisition, utilization, and synthesis of data from their tracking systems, state-based birth defects surveillance programs play a key role in planning, prevention, education, support, and research activities.[4] Collectively, they are charged with supplying clinicians, public health practitioners, policymakers, and research scientists with information that can be used to monitor trends, identify causes and risk factors, evaluate prevention efforts, recognize underserved or disproportionately affected populations, and determine the resources necessary to support individuals and families with birth defects.[5] High-quality data are essential to all of these functions. The National Birth Defects Prevention Network, in its comprehensive Guidelines for Conducting Birth Defects Surveillance, identifies 3 key indicators that can be used to assess data quality: completeness, accuracy, and timeliness.[5]

The Florida Birth Defects Registry (FBDR), operated by the Florida Department of Health (FDOH) and its partners, is one of the largest population-based state registries in the United States. The FBDR has tracked structural, functional, and biochemical abnormalities since 1998, covering more than 3 million births in a 14-year period. Data from the FBDR have been used extensively in local, state, and national reports, etiologic investigations, and health services research studies.[6-11] Although Florida also operates enhanced surveillance activities in specific counties and on selected defects, its comprehensive, statewide system uses a passive case ascertainment methodology relying almost exclusively on linkage of administrative data sources that

[a]Department of Family and Community Medicine, Baylor College of Medicine, Houston, Texas. [b]Birth Defects Surveillance Program, Department of Community and Family Health, College of Public Health, University of South Florida, Tampa, Florida. [c]Florida Birth Defects Registry, Bureau of Epidemiology, Florida Department of Health, Tallahassee, Florida.

Address correspondence to Jason L. Salemi, PhD, MPH; Baylor College of Medicine, 3701 Kirby Dr., Suite 600 (MS: BCM700), Houston, TX 77098. Telephone: (713) 798-4698. Email: jason.salemi@bcm.edu.

contain diagnostic indicators for birth defects. Therefore, the FBDR has been committed to understanding the completeness and accuracy of its data. In 2011, facing funding cuts and an elimination of data sources, Salemi et al analyzed the relative contribution of each data source and found that the anticipated loss of several service-related data sets would only result in a 5% loss of all cases, but that the loss would vary greatly by defect and would be disproportionately higher in particular sociodemographic subgroups.[12] Using capture-recapture techniques, the FBDR was also able to link together data from its passive registry with an enhanced surveillance project to report on the FDBR's completeness of ascertainment, which was 86.6% overall and ranged from 45.6% for anencephaly to 88.6% for Down syndrome.[13] Tanner et al found that by adding infant death certificates as an FBDR data source, completeness could be improved, particularly for defects with a high and early case-fatality rate.[14] Most recently, a statewide case confirmation project was used to report on the FBDR's accuracy for diagnosing 13 major birth defects.[15]

Timeliness—the extent to which surveillance data are rapid, prompt, and responsive[5]—has been a major limitation of the FBDR. Timeliness is particularly important if a program is to provide current rate and trend data, and information used to respond quickly to investigative inquiries, and refer affected families to services.[16,17] Currently, the FBDR's primary data sources, hospital inpatient and ambulatory discharge records, are released quarterly with a 6-month lag time. In addition, the FBDR's current case definition includes diagnosis of a birth defect at any point during the first year of life. Therefore, the final register of infants born with birth defects is not complete until approximately 18 months after the last infant in the annual birth cohort has been born. Surveillance programs often face difficult decisions regarding the timeliness of their data, since improvements in timeliness often require sacrificing completeness or some other element of data quality.

The goal of this study was to determine if the timeliness of the FBDR could be improved without significantly reducing the completeness of birth defects ascertainment. First, we investigated the timing of diagnosis of specific defects by reconstructing the FBDR using various periods of follow-up for each infant (relative to the current follow-up of 1 year). Second, we considered various scenarios in which less data were used to construct the FBDR (less wait time, more timely registry), and assessed the resultant change in completeness. Last, we analyzed whether the timeliness-completeness relationship varied across defects and sociodemographic and perinatal subgroups.

Methods and Materials

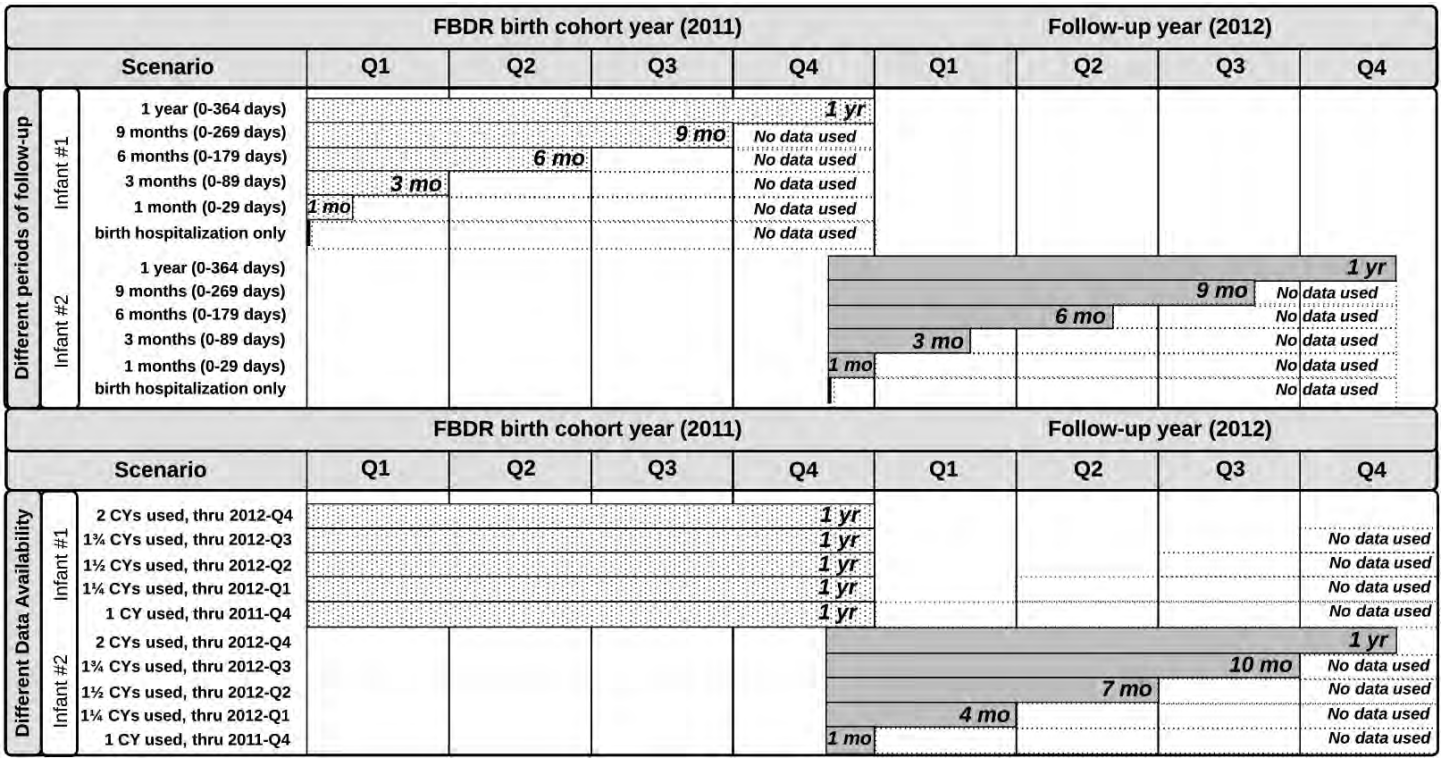
Data Sources

The current evaluation focused on data from the FBDR, Florida's passive, statewide, population-based birth defects surveillance system. The FDOH, in collaboration with the University of South Florida Birth Defects Surveillance Program, has also operated several enhanced surveillance projects that are constrained to selected counties, a subset of birth defects, or a particular time frame. These data have been used extensively in research, referral to services, evaluation assessments, and case-confirmation protocols.[13,18] However, since only data from the statewide, passive system are currently used for official frequencies and prevalence rates of birth defects in Florida, published annually in Birth Defects Research, Part A,[9] the evaluation was limited to these data. Although the component sources and linkage methodology have changed over time, the FBDR has always been constructed using a hierarchical, stepwise data linkage strategy[19] to combine information from several existing administrative data sources. These data sources have included: 1) Florida Bureau of Vital Statistics birth (1998–2011) and infant death (2009–2011) records, 2) Agency for Health Care Administration (AHCA) inpatient (1998–2011), outpatient (1998–2011), and emergency department (2010–2011) hospital discharge records, and 3) Children's Medical Services (CMS) Regional Perinatal Intensive Care Center data (1998–2008), Early Steps program data (1998–2008), and Minimum Data Set (encounter-level, service-related) records (1998–2007). We have discussed previously the nature and use of each of these data sources in constructing the FBDR.[12] Briefly, birth certificates are used to define the source population from which the registry is created, namely all infants born alive to a Florida-resident mother. All other data sources contain International Classification of Diseases, ninth edition, Clinical Modification (ICD-9-CM) diagnosis codes that are used to identify birth defects, with the exception of infant death certificates which instead contain tenth edition (ICD-10) diagnosis codes. The final FBDR is created annually and consists of an unduplicated inventory of infants with 1 or more "included" birth defect codes (primarily but not restricted to ICD-9-CM code range 740-759 and ICD-10 "Q" codes).

Timing of Diagnosis

This evaluation focuses on time and depends on answers to the "when" questions. When are different birth defects diagnosed? When do data sources used to construct the FBDR become available? When is a state-based surveillance program considered to be timely regarding release of its data? Not all birth defects are diagnosed at birth. Currently, an FBDR case is an infant who is diagnosed with a birth defect at any point during the first year of life (0–364 days). To be complete, the FBDR must follow each infant, through record linkage, for 1 year. Therefore, although only 1 year of birth certificate data is required to define the population of interest, 2 full years of the supplemental data sources (eg, hospital discharge data) are required. For example, the 2011 FBDR would consist of infants born throughout the 2011 calendar year. For an infant born on December 31, 2011, hospital visits, service encounters, and occurrences of death must be followed through December 31, 2012 to capture all ICD-9/10 codes documented in the first year of life that may be indicative of a birth defect. By the time the complete data sources are ascertained, cleaned, linked, validated, and compiled, there is approximately an 18-month lag from the last birth in the cohort to the finalization of the FBDR data set.

Figure 1. Scenarios Representing the Effect of Different Periods of Follow-up (top panel) and Different Data Availability (bottom panel) on Total Follow-Up Time for Infants in the 2011 Florida Birth Defects Registry Cohort



Dotted horizontal bars: infant #1 born January 1, 2011; *Gray horizontal bars:* infant #2 born December 1, 2011.

The length of each bar corresponds to the length of follow-up. Total follow-up time under each scenario is written at the rightmost end of each bar. When varying the length of follow-up, the follow-up time is the exact same for all infants, regardless of when they were born during the calendar year. When varying the amount of data used to compile the registry, follow-up time is different for each infant depending on the amount of data available and when they were born during the calendar year. The maximum follow-up time under any scenario is 1 year, corresponding to the maximum follow-up time for the Florida Birth Defects Registry. For all analyses, infants were unduplicated at the level of the defect; however, an infant with multiple defects considered in this study will be included in more than one defect-specific analysis.

CY, calendar year (refers to the amount of hospital discharge data from AHCA that would be used to create the Florida Birth Defects Registry).

Data Analysis

The FBDR was reconstructed using information concerning the timing of each event—defined as an encounter that generates a record in one of the source data files—in which a birth defect could be diagnosed. Therefore, we restricted our investigation to hospital discharge data (inpatient, ambulatory, and emergency department) sources in which we were able to determine the timing of each encounter. Other data sources only had an indicator of whether the encounter occurred within the first year of life, not the exact timing. In our previous assessment of the impact of a changing case ascertainment net on the FBDR's completeness, we found that restricting to hospital discharge data alone would still capture 95% of all cases reported by the FBDR.[12] We also restricted the analytic time frame to 2006–2011 to eliminate the effect of the discharge data sources' expansion from 10 to 31 captured ICD-9-CM diagnosis codes which increases the likelihood birth defects will be captured.

We first investigated the timing of diagnosis of birth defects by estimating the effect of different periods of follow-up on prevalence rates reported by the FBDR. To be included in the reconstructed FBDR, the date of admission for an encounter must have occurred within the specified time frame using the infant's date of birth as the starting point. Five different scenarios with progressively shorter follow-up windows were considered (Figure 1):

1. What if the FBDR only followed each infant for 9 months (0–269 days)?
2. What if the FBDR only followed each infant for 6 months (0–179 days)?
3. What if the FBDR only followed each infant for 3 months (0–89 days)?
4. What if the FBDR only followed each infant for 1 month (0–29 days)?
5. What if the FBDR only considered each infant's birth hospitalization?

To illustrate the process, consider an infant born on December 20, 2011 who would be captured within the 2011 FBDR cohort. The current construction of the FBDR includes a complete year of follow-up (0–364 days); therefore, all birth defect diagnoses taking place during inpatient, ambulatory, and emergency department encounters for the infant in which the admission occurred between December 20, 2011 and December 18, 2012 would be considered. For scenario 1 above, the reconstruction of the FBDR for this infant would include only those diagnoses from admissions between December 20, 2011 and September 14, 2012 (0–269

days). For scenarios 2–4, only those diagnoses from admissions between December 20, 2011 and either June 16, 2012 (scenario 2: 0–179 days), March 18, 2012 (scenario 3: 0–89 days), or January 18, 2012 (scenario 4: 0–29 days) would be considered. For scenario 5, only diagnoses made during the birth hospitalization would be captured and used to determine whether the infant has an FBDR-included birth defect (Figure 1).

For each scenario, we recalculated the prevalence rate as the number of cases per 10,000 resident live births; 95% confidence intervals (CI) were estimated using a Poisson distribution. Each scenario was compared to the "current FBDR" in which infants are followed for 1 year (0–364 days, or until death, if sooner). First, we calculated the completeness of ascertainment as the (hypothetical rate / current FBDR rate) × 100. Next, we assessed whether the recalculated rates were statistically significantly different from the current FBDR by determining whether the 95% CI for the recalculated rate included the current FBDR rate (considered the "truth").

We also considered a more realistic scenario in which follow-up was dictated not by a prespecified period of follow-up for each infant, but instead by data available at a particular point in time. In an effort to make the FBDR timelier (less than an 18-month lag), fewer data are compiled. Follow-up time for infants in this scenario depends on when they were born and how much data are included. If only the current FBDR year's data were used, infants born on January 1 would have exactly 1 year of potential follow-up, whereas infants born on December 31 would only have their birth hospitalization considered. Four different scenarios with decreasing amounts of available data were considered (Figure 1).

1. What if the FBDR were constructed with a 15-month time lag, using all data from the current FBDR calendar year and 3 quarters from the next year, through September 30?
2. What if the FBDR were constructed with a 12-month time lag, using all data from the current FBDR calendar year and 2 quarters from the next year, through June 30?
3. What if the FBDR were constructed with a 9-month time lag, using all data from the current FBDR calendar year and 1 quarter from the next year, through March 31?
4. What if the FBDR were constructed with a 6-month time lag, using only data from the current FBDR calendar year?

To illustrate the process for this set of scenarios, we reconsider an infant born on December 20, 2011. The current construction of the FBDR includes all data from the current FBDR calendar year (2011) and all data from the next calendar year (2012); therefore, all birth defect diagnoses taking place during inpatient, ambulatory, and emergency department encounters for the infant in which the admission occurred between December 20, 2011 and December 31, 2012 would be considered. For scenario 1 above, the reconstruction of the FBDR for this infant would include only those diagnoses from admissions between December 20, 2011 and September 30, 2012 (using data through third quarter 2012). For scenarios 2–4, only those diagnoses from admissions between December 20, 2011 and either June 30, 2012 (scenario 2: using data through second quarter 2012), March 31, 2012 (scenario 3: using data through first quarter 2012), or December 31, 2011 (scenario 4: using data only from current calendar year) would be considered (Figure 1).

To assess the impact of producing a timelier FBDR on its completeness of ascertainment, we used the same strategy as for the assessment of the impact of the different follow-up times described above. All analyses were performed for "any FBDR defect" as well as for 44 specific defects and 4 defect groups: neural tube defects (NTD), orofacial clefts, all congenital heart defects (CHD), and critical congenital heart defects (CCHD) (Appendix A). We also explored, for each of the aforementioned scenarios, the degree to which the impact of follow-up time and data availability on the proportion of cases missed (relative to the current FBDR) differed across demographic and perinatal characteristics, using data obtained from the infant's birth certificate. Maternal age in years was categorized as <20, 20–29, 30–39, and ≥40. Race/ethnicity of the biological mother was first grouped by ethnicity (Hispanic vs non-Hispanic [NH]) with the NH group subdivided into white, black, and other. The principal payer for the delivery was either Medicaid, private insurance, self-pay, or other (including charity). The revised graduated index algorithm (R-GINDEX),[20] which assesses the adequacy of prenatal care from the trimester prenatal care began, the total number of prenatal care visits, and gestational age, was used to classify women as having adequate/intensive, intermediate, or inadequate/no prenatal care. We also compared differences by birth weight in grams (<1500, 1500–2499, ≥2500), gestational age in weeks (<32, 32–36, ≥37), plurality (singleton vs multiple), method of delivery (vaginal vs cesarean section), and infant sex. For all analyses, infants were unduplicated at the level of the defect; however, an infant with multiple defects considered in this study will be included in more than 1 defect-specific analysis. All inferential tests were 2-tailed with a 5% type I error rate, and analyses were conducted using SAS software version 9.4 (SAS Institute, Inc).

Results

During the 6-year study period, the FBDR identified 27,603 infants with ≥1 birth defect included in this study that was identified during the first year of life, or 1 affected infant in every 49 resident live births (Table 1). Nearly 38% of affected infants had a CHD, the most common defect class, with ventricular septal defects being the most common individual defect. Overall, shortening the length of follow-up for each infant to progressively shorter periods had a small-to-moderate effect on the completeness of ascertainment of the FBDR (Table 1). Compared to the current FBDR's follow-up (1 year), restricting follow-up to 9 months would only result in a loss of 1.4% of cases; similarly cutting follow-up to 6 months would lose 3.2% of cases. However, if only the birth hospitalization were used for case ascertainment, the FBDR would miss nearly 7,000 (25.1%) cases that it currently captures.

Table 1. The Effect of Different Periods of Follow-up on Prevalence Rates[a] Reported by the Florida Birth Defects Registry, by Defect Category, 2006–2011

Birth Defect	*Current FBDR*	*Follow-up 9 Months*	*Follow-up 6 Months*	*Follow-up 3 Months*	*Follow-up 1 Month*	*Follow-up Birth Hosp Only*
	Rate (cases)	*Rate (% comp[b])*	*Rate (% comp[b])*	*Rate (% comp[b])*	*Rate (% comp[b])*	*Rate (% comp[b])*
Anencephaly	0.38 (51)	0.37 (98.0%)	0.36 (96.1%)	0.35 (92.2%)	0.34 (90.2%)	0.34 (90.2%)
Aniridia	0.05 (7)	0.04 (85.7%)	0.04 (85.7%)	0.04 (85.7%)	0.04 (71.4%)	0.03 (57.1%)
Anophthalmia/microphthalmia	0.76 (103)	0.75 (98.1%)	0.73 (95.1%)	0.67 (88.3%)	**0.59 (77.7%)**	**0.53 (69.9%)**
Anotia/microtia	0.68 (92)	0.67 (97.8%)	0.63 (92.4%)	0.60 (88.0%)	0.59 (87.0%)	0.55 (80.4%)
Aortic valve stenosis	1.35 (182)	1.33 (98.4%)	1.29 (95.6%)	**1.15 (85.2%)**	**1.06 (78.6%)**	**0.84 (62.1%)**
Biliary atresia	0.93 (125)	0.93 (100.0%)	0.89 (96.0%)	0.82 (88.0%)	**0.39 (42.4%)**	**0.29 (31.2%)**
Bladder exstrophy	0.27 (36)	0.27 (100.0%)	0.26 (97.2%)	0.26 (97.2%)	0.24 (91.7%)	0.24 (91.7%)
Choanal atresia	1.53 (207)	1.52 (99.0%)	1.48 (96.6%)	1.39 (90.8%)	**1.32 (86.0%)**	**1.14 (74.4%)**
Cloacal exstrophy	6.20 (836)	6.07 (98.0%)	5.84 (94.1%)	**5.56 (89.7%)**	**5.32 (85.8%)**	**4.36 (70.3%)**
Clubfoot	12.43 (1,676)	12.34 (99.3%)	12.19 (98.1%)	12.00 (96.6%)	**11.72 (94.3%)**	**11.43 (92.0%)**
Coarctation of the aorta	6.64 (896)	6.61 (99.6%)	6.48 (97.5%)	**6.12 (92.1%)**	**5.41 (81.5%)**	**4.09 (61.5%)**
Common truncus	0.67 (90)	0.66 (98.9%)	0.64 (95.6%)	0.64 (95.6%)	0.60 (90.0%)	**0.44 (66.7%)**
Congenital cataract	1.16 (157)	1.13 (96.8%)	1.04 (89.2%)	**0.92 (79.0%)**	**0.74 (63.7%)**	**0.67 (57.3%)**
Congenital posterior urethral valves	1.31 (177)	1.26 (96.0%)	1.19 (91.0%)	1.12 (85.3%)	**0.99 (75.7%)**	**0.66 (50.3%)**
Deletion 22 q11.2	0.33 (45)	0.33 (97.8%)	0.31 (93.3%)	0.27 (80.0%)	**0.23 (68.9%)**	**0.16 (46.7%)**
Diaphragmatic hernia	2.88 (389)	2.81 (97.4%)	2.70 (93.6%)	**2.58 (89.5%)**	**2.47 (85.6%)**	**2.22 (77.1%)**
Double outlet right ventricle	2.24 (302)	2.22 (99.0%)	2.05 (91.7%)	**1.74 (77.8%)**	**1.58 (70.5%)**	**1.25 (55.6%)**
Ebstein anomaly	0.62 (83)	0.60 (97.6%)	0.60 (97.6%)	0.58 (94.0%)	0.56 (90.4%)	**0.48 (78.3%)**
Encephalocele	0.86 (116)	0.85 (98.3%)	0.79 (92.2%)	0.73 (85.3%)	**0.70 (81.0%)**	**0.65 (75.0%)**
Endocardial cushion defect	3.92 (528)	3.80 (97.0%)	3.62 (92.4%)	**3.23 (82.6%)**	**2.95 (75.4%)**	**2.56 (65.3%)**
Esophageal atresia/tracheoesophageal fistula	2.14 (288)	2.12 (99.3%)	2.08 (97.6%)	2.07 (96.9%)	2.04 (95.5%)	**1.86 (87.2%)**
Gastroschisis	4.46 (601)	4.44 (99.7%)	4.43 (99.5%)	4.43 (99.3%)	4.43 (99.3%)	4.38 (98.3%)
Holoprosencephaly	3.96 (534)	3.83 (96.8%)	3.69 (93.3%)	**3.37 (85.2%)**	**3.03 (76.6%)**	**2.64 (66.7%)**
Hydrocephalus without spina bifida	6.91 (932)	6.68 (96.7%)	**6.44 (93.1%)**	**5.95 (86.1%)**	**5.55 (80.3%)**	**5.07 (73.4%)**
Hypoplastic left heart syndrome	2.85 (384)	2.83 (99.2%)	2.70 (94.8%)	**2.52 (88.5%)**	**2.42 (84.9%)**	**2.07 (72.7%)**
Hypospadias	33.79 (4,557)	**32.65 (96.6%)**	**31.42 (93.0%)**	**31.07 (91.9%)**	**30.79 (91.1%)**	**30.42 (90.0%)**
Interrupted aortic arch	0.62 (84)	0.62 (98.8%)	0.59 (95.2%)	0.55 (88.1%)	0.51 (82.1%)	**0.33 (52.4%)**

Table 1, cont. The Effect of Different Periods of Follow-up on Prevalence Rates[a] Reported by the Florida Birth Defects Registry, by Defect Category, 2006–2011

Birth Defect	*Current FBDR*	*Follow-up 9 Months*	*Follow-up 6 Months*	*Follow-up 3 Months*	*Follow-up 1 Month*	*Follow-up Birth Hosp Only*
	Rate (cases)	*Rate (% comp[b])*	*Rate (% comp[b])*	*Rate (% comp[b])*	*Rate (% comp[b])*	*Rate (% comp[b])*
Limb deficiencies (reduction defects)	3.40 (459)	3.35 (98.5%)	3.27 (96.1%)	3.21 (94.3%)	3.12 (91.7%)	**3.00 (88.0%)**
Pulmonary valve atresia and stenosis	9.61 (1,296)	9.31 (96.8%)	**8.95 (93.1%)**	**8.24 (85.7%)**	**7.29 (75.8%)**	**6.18 (64.3%)**
Pyloric stenosis	25.98 (3,504)	25.96 (99.9%)	25.94 (99.8%)	25.48 (98.1%)	**9.87 (38.0%)**	**0.37 (1.4%)**
Rectal and large intestinal atresia/stenosis	4.10 (553)	4.05 (98.7%)	3.92 (95.7%)	3.80 (92.8%)	**3.68 (89.7%)**	**3.36 (81.9%)**
Renal agenesis/hypoplasia	4.39 (592)	4.25 (96.8%)	4.12 (93.8%)	**3.98 (90.7%)**	**3.74 (85.1%)**	**3.52 (80.2%)**
Single ventricle	1.22 (165)	1.17 (95.8%)	**1.00 (81.8%)**	**0.73 (60.0%)**	**0.61 (49.7%)**	**0.49 (40.0%)**
Small intestinal atresia/stenosis	4.98 (671)	4.95 (99.6%)	4.91 (98.7%)	4.83 (97.0%)	4.76 (95.7%)	**3.96 (79.6%)**
Spina bifida without anencephalus	2.63 (355)	2.56 (97.2%)	2.44 (92.7%)	**2.29 (87.0%)**	**2.16 (82.0%)**	**2.10 (79.7%)**
Tetralogy of Fallot	4.77 (643)	4.74 (99.4%)	4.51 (94.6%)	**3.91 (82.0%)**	**3.66 (76.7%)**	**3.14 (65.8%)**
Total anomalous pulmonary venous connection	0.95 (128)	0.92 (96.9%)	0.89 (93.8%)	0.81 (85.2%)	**0.70 (73.4%)**	**0.48 (50.8%)**
Transposition of the great arteries	2.59 (349)	2.56 (98.9%)	2.48 (95.7%)	2.34 (90.3%)	**2.22 (86.0%)**	**1.88 (72.5%)**
Tricuspid valve atresia and stenosis	1.08 (145)	1.07 (99.3%)	1.03 (95.9%)	0.97 (90.3%)	0.90 (84.1%)	**0.78 (72.4%)**
Trisomy 13	0.65 (88)	0.65 (98.9%)	0.62 (94.3%)	0.60 (92.0%)	0.57 (87.5%)	0.53 (80.7%)
Trisomy 18	1.59 (215)	1.59 (99.5%)	1.57 (98.6%)	1.53 (95.8%)	1.48 (92.6%)	1.41 (88.4%)
Trisomy 21	12.32 (1,662)	12.17 (98.7%)	11.89 (96.5%)	**11.55 (93.7%)**	**11.15 (90.5%)**	**10.68 (86.7%)**
Turner syndrome	0.67 (91)	0.66 (97.8%)	0.65 (95.6%)	0.62 (92.3%)	0.60 (89.0%)	0.56 (83.5%)
Ventricular septal defect	56.75 (7,653)	56.25 (99.1%)	55.48 (97.8%)	**53.76 (94.7%)**	**51.53 (90.8%)**	**47.39 (83.5%)**
Any critical congenital heart defect[c]	19.20 (2,590)	19.13 (99.6%)	18.69 (97.3%)	**17.53 (91.3%)**	**16.31 (84.9%)**	**13.44 (70.0%)**
Any congenital heart defect[c]	77.51 (10,454)	76.86 (99.2%)	**75.91 (97.9%)**	**73.73 (95.1%)**	**70.17 (90.5%)**	**63.69 (82.2%)**
Any neural tube defect[c]	3.77 (508)	3.67 (97.4%)	3.51 (93.3%)	**3.31 (87.8%)**	**3.14 (83.3%)**	**3.03 (80.3%)**
Any orofacial cleft[c]	12.35 (1,665)	12.00 (97.2%)	**11.63 (94.2%)**	**11.28 (91.4%)**	**11.00 (89.1%)**	**10.71 (86.8%)**
Any FBDR defect[c]	204.67 (27,603)	**201.76 (98.6%)**	**198.18 (96.8%)**	**193.50 (94.5%)**	**172.25 (84.2%)**	**153.33 (74.9%)**

FBDR, Florida Birth Defects Registry.

Bolded values represent recalculated rates whose 95% confidence intervals did not contain the rate reported in the "current FBDR" column.

[a]Cases per 10,000 resident live births

[b]Percent complete calculated as: (hypothetical rate / current FBDR rate) ×100.

[c]See Appendix A for a description of the defects included in each composite defect category. For all analyses, infants were unduplicated at the level of the defect; however, an infant with multiple defects considered in this study will be included in more than one defect-specific analysis.

Table 2. The Effect of Data Availability on Prevalence Rates[a] Reported by the Florida Birth Defects Registry, by Defect Category, 2006–2011

Birth Defect	*Current FBDR*	*Year 2 Quarter 3*	*Year 2 Quarter 2*	*Year 2 Quarter 1*	*Year 1 Only*
	Rate (cases)	*Rate (% comp[b])*	*Rate (% comp[b])*	*Rate (% comp[b])*	*Rate (% comp[b])*
Estimated timeliness (months delay[c])	**18 (least timely)**	**15**	**12**	**9**	**6 (most timely)**
Anencephaly	0.38 (51)	0.38 (100.0%)	0.37 (98.0%)	0.36 (96.1%)	0.36 (96.1%)
Aniridia	0.05 (7)	0.05 (100.0%)	0.05 (100.0%)	0.04 (85.7%)	0.04 (71.4%)
Anophthalmia/microphthalmia	0.76 (103)	0.76 (100.0%)	0.76 (99.0%)	0.75 (98.1%)	0.70 (91.3%)
Anotia/microtia	0.68 (92)	0.67 (98.9%)	0.67 (97.8%)	0.65 (94.6%)	0.63 (92.4%)
Aortic valve stenosis	1.35 (182)	1.33 (98.9%)	1.33 (98.9%)	1.30 (96.2%)	1.25 (92.3%)
Biliary atresia	0.93 (125)	0.93 (100.0%)	0.92 (99.2%)	0.89 (96.0%)	0.79 (85.6%)
Bladder exstrophy	0.27 (36)	0.27 (100.0%)	0.27 (100.0%)	0.27 (100.0%)	0.26 (97.2%)
Choanal atresia	1.53 (207)	1.53 (100.0%)	1.52 (99.0%)	1.48 (96.6%)	1.43 (93.2%)
Cloacal exstrophy	6.20 (836)	6.19 (99.9%)	6.14 (99.0%)	6.03 (97.2%)	5.84 (94.3%)
Clubfoot	12.43 (1,676)	12.41 (99.9%)	12.35 (99.3%)	12.26 (98.6%)	12.16 (97.9%)
Coarctation of the aorta	6.64 (896)	6.64 (100.0%)	6.63 (99.8%)	6.54 (98.4%)	6.21 (93.5%)
Common truncus	0.67 (90)	0.67 (100.0%)	0.66 (98.9%)	0.65 (97.8%)	0.65 (96.7%)
Congenital cataract	1.16 (157)	1.16 (100.0%)	1.16 (100.0%)	1.10 (94.3%)	0.99 (85.4%)
Congenital posterior urethral valves	1.31 (177)	1.31 (99.4%)	1.27 (96.6%)	1.24 (94.4%)	1.19 (90.4%)
Deletion 22 q11.2	0.33 (45)	0.33 (100.0%)	0.33 (100.0%)	0.31 (93.3%)	0.30 (88.9%)
Diaphragmatic hernia	2.88 (389)	2.88 (100.0%)	2.85 (98.7%)	2.80 (97.2%)	2.67 (92.5%)
Double outlet right ventricle	2.24 (302)	2.23 (99.7%)	2.22 (99.0%)	2.16 (96.4%)	2.02 (90.1%)
Ebstein anomaly	0.62 (83)	0.62 (100.0%)	0.61 (98.8%)	0.60 (97.6%)	0.59 (96.4%)
Encephalocele	0.86 (116)	0.86 (100.0%)	0.85 (99.1%)	0.82 (95.7%)	0.79 (91.4%)
Endocardial cushion defect	3.92 (528)	3.89 (99.4%)	3.83 (97.9%)	3.73 (95.3%)	**3.47 (88.6%)**
Esophageal atresia/ tracheoesophageal fistula	2.14 (288)	2.14 (100.0%)	2.13 (99.7%)	2.12 (99.3%)	2.09 (97.9%)
Gastroschisis	4.46 (601)	4.46 (100.0%)	4.45 (99.8%)	4.44 (99.7%)	4.43 (99.3%)
Holoprosencephaly	3.96 (534)	3.94 (99.4%)	3.89 (98.3%)	3.79 (95.7%)	**3.54 (89.5%)**
Hydrocephalus without spina bifida	6.91 (932)	6.89 (99.7%)	6.83 (98.8%)	6.64 (96.0%)	**6.24 (90.3%)**
Hypoplastic left heart syndrome	2.85 (384)	2.85 (100.0%)	2.84 (99.7%)	2.78 (97.7%)	2.68 (94.3%)
Hypospadias	33.79 (4,557)	33.66 (99.6%)	33.29 (98.5%)	**32.59 (96.4%)**	**31.80 (94.1%)**
Interrupted aortic arch	0.62 (84)	0.62 (100.0%)	0.62 (98.8%)	0.58 (92.9%)	0.56 (90.5%)

Table 2, cont. The Effect of Data Availability on Prevalence Rates[a] Reported by the Florida Birth Defects Registry, by Defect Category, 2006–2011

Birth Defect	*Current FBDR*	*Year 2 Quarter 3*	*Year 2 Quarter 2*	*Year 2 Quarter 1*	*Year 1 Only*
	Rate (cases)	*Rate (% comp[b])*	*Rate (% comp[b])*	*Rate (% comp[b])*	*Rate (% comp[b])*
Estimated timeliness (months delay[c])	**18 (least timely)**	**15**	**12**	**9**	**6 (most timely)**
Limb deficiencies (reduction defects)	3.40 (459)	3.39 (99.6%)	3.37 (98.9%)	3.34 (98.0%)	3.26 (95.6%)
Pulmonary valve atresia and stenosis	9.61 (1,296)	9.59 (99.8%)	9.45 (98.3%)	9.17 (95.4%)	**8.71 (90.7%)**
Pyloric stenosis	25.98 (3,504)	25.98 (100.0%)	25.96 (99.9%)	25.93 (99.8%)	**23.27 (89.6%)**
Rectal and large intestinal atresia/ stenosis	4.10 (553)	4.09 (99.6%)	4.07 (99.3%)	4.00 (97.5%)	3.94 (96.2%)
Renal agenesis/hypoplasia	4.39 (592)	4.38 (99.8%)	4.35 (99.0%)	4.26 (97.0%)	4.08 (92.9%)
Single ventricle	1.22 (165)	1.22 (99.4%)	1.19 (97.0%)	1.11 (90.9%)	**0.95 (77.6%)**
Small intestinal atresia/stenosis	4.98 (671)	4.96 (99.7%)	4.95 (99.6%)	4.95 (99.6%)	4.88 (98.1%)
Spina bifida without anencephalus	2.63 (355)	2.63 (100.0%)	2.61 (99.2%)	2.55 (96.9%)	2.42 (92.1%)
Tetralogy of Fallot	4.77 (643)	4.77 (100.0%)	4.74 (99.4%)	4.55 (95.3%)	**4.27 (89.6%)**
Total anomalous pulmonary venous connection	0.95 (128)	0.94 (99.2%)	0.94 (99.2%)	0.93 (97.7%)	0.87 (91.4%)
Transposition of the great arteries	2.59 (349)	2.59 (100.0%)	2.57 (99.4%)	2.51 (97.1%)	2.42 (93.4%)
Tricuspid valve atresia and stenosis	1.08 (145)	1.08 (100.0%)	1.07 (99.3%)	1.05 (97.9%)	1.02 (95.2%)
Trisomy 13	0.65 (88)	0.65 (98.9%)	0.65 (98.9%)	0.62 (94.3%)	0.61 (93.2%)
Trisomy 18	1.59 (215)	1.59 (100.0%)	1.59 (99.5%)	1.58 (99.1%)	1.56 (97.7%)
Trisomy 21	12.32 (1,662)	12.31 (99.9%)	12.24 (99.3%)	12.12 (98.4%)	11.79 (95.7%)
Turner syndrome	0.67 (91)	0.67 (98.9%)	0.66 (97.8%)	0.66 (97.8%)	0.65 (95.6%)
Ventricular septal defect	56.75 (7,653)	56.70 (99.9%)	56.52 (99.6%)	55.99 (98.7%)	**54.69 (96.4%)**
Any critical congenital heart defect[d]	19.20 (2,590)	19.19 (99.9%)	19.14 (99.7%)	18.83 (98.0%)	**18.11 (94.3%)**
Any congenital heart defect[d]	77.51 (10,454)	77.45 (99.9%)	77.20 (99.6%)	76.57 (98.8%)	**74.92 (96.7%)**
Any neural tube defect[d]	3.77 (508)	3.77 (100.0%)	3.74 (99.2%)	3.65 (96.9%)	3.48 (92.5%)
Any orofacial cleft[d]	12.35 (1,665)	12.32 (99.8%)	12.20 (98.8%)	11.95 (96.8%)	**11.58 (93.8%)**
Any FBDR defect[d]	204.67 (27,603)	204.35 (99.8%)	203.38 (99.4%)	**201.10 (98.3%)**	**194.55 (95.1%)**

FBDR, Florida Birth Defects Registry.

Bolded values represent recalculated rates whose 95% confidence intervals did not contain the rate reported in the "current FBDR" column.

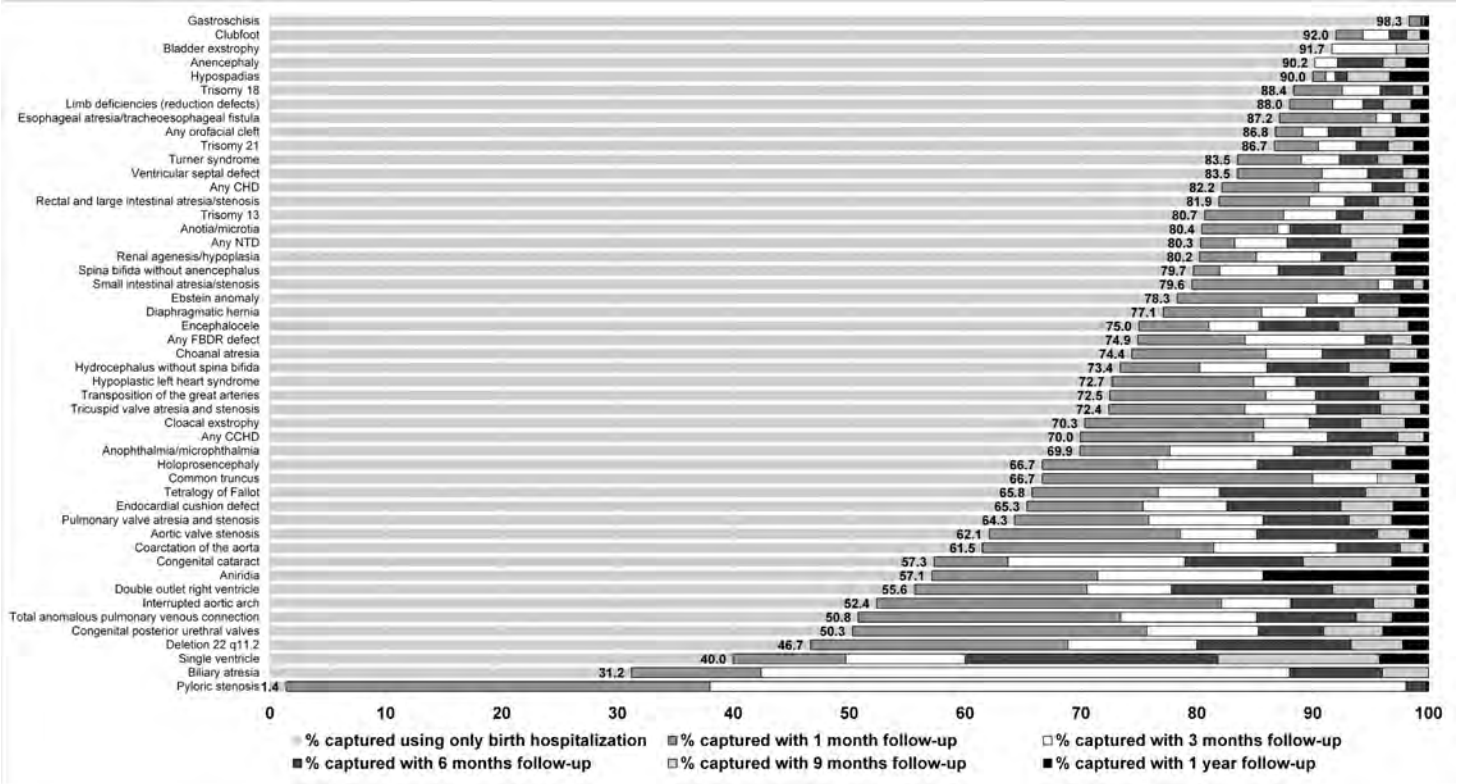
[a]Cases per 10,000 resident live births

[b]Percent complete calculated as: (hypothetical rate / current FBDR rate) *100.

[c]Estimated number of months elapsed between last birth in an annual cohort and creation of the FBDR for that cohort

[d]See Appendix A for a description of the defects included in each composite defect category. For all analyses, infants were unduplicated at the level of the defect; however, an infant with multiple defects considered in this study will be included in more than one defect-specific analysis.

Figure 2. The Effect of Differential Periods of Follow-up on the Proportion of Cases Captured by the Florida Birth Defects Registry, by Defect Category, 2006–2011



Y-axis: Birth defect category.

X-axis: Proportion of cases captured.

Defect categories are sorted by the proportion of cases captured by restricting follow-up to the duration of the birth hospitalization, relative to cases captured by the current FBDR (which incorporates a 1-year follow-up time period). For a given defect, each color represents the additional cases captured, relative to the previous restriction in follow-up. For all analyses, infants were unduplicated at the level of the defect; however, an infant with multiple defects considered in this study will be included in more than 1 defect-specific analysis.

FBDR, Florida Birth Defects Registry.

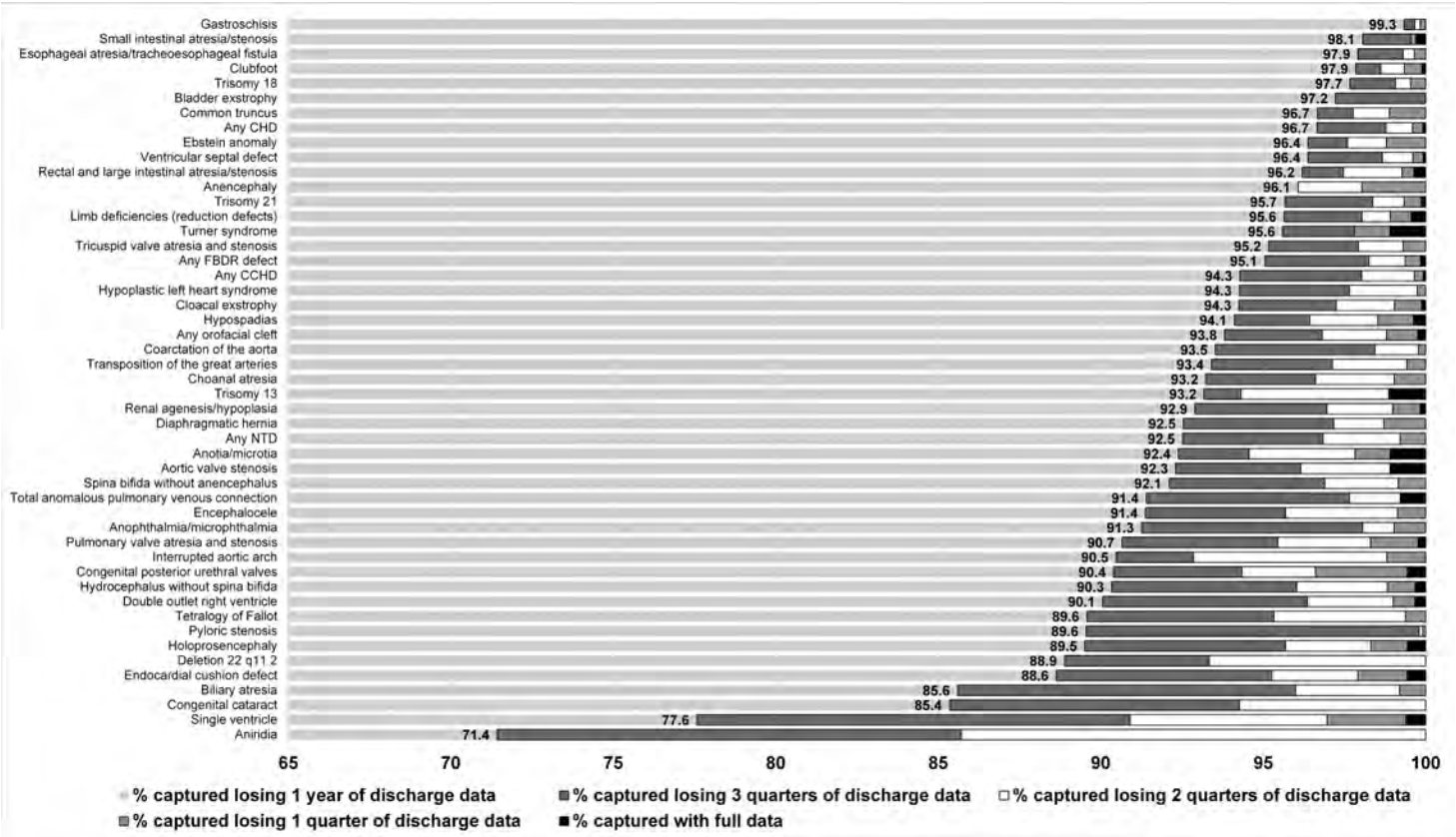
As expected, there was significant variation across defects in the impact of shortening follow-up on completeness (Table 1, Figure 2). Defects that are easily identifiable and more likely to be diagnosed at birth were least affected, exemplified by gastroschisis, clubfoot, bladder exstrophy, and anencephaly which would still be 98.3%, 92.0%, 91.7%, and 90.2% complete, respectively, even with restriction of follow-up for each infant to the birth hospitalization. Conversely, a defect such as pyloric stenosis, which is often diagnosed after presentation of symptoms in the newborn (eg, excessive vomiting), would be affected significantly by restricting to the birth hospitalization, capturing only 1.4% of current FBDR cases.

It is important to note 27 of 44 (61.3%) individual defects with at least 10 total cases would have had less than a 2% loss (all had <5% loss) by limiting follow-up to 9 months, with only hypospadias having a statistically significantly different rate from the current FBDR. Only 3 additional defects (hydrocephalus without spina bifida, pulmonary valve atresia/stenosis, and single ventricle) and the "any CHD" group would have a significantly lower reported prevalence by cutting follow-up in half to 6 months. The prevalence rates of all but 8 defects would be significantly lower than the current FBDR if case ascertainment only included diagnoses made during the birth hospitalization.

Improving the timeliness of the FBDR by compiling the registry with less data had a small impact on completeness of ascertainment (Table 2). Overall, compiling the FBDR with only 6 quarters of AHCA data (as opposed to 8 quarters) would improve timeliness by approximately 6 months, resulting in a registry that is 99.4% complete. None of the defects studied would have prevalence rates significantly different from those currently reported by the FBDR. Restricting to 5 quarters of data and improving timeliness by 9 months would reduce completeness to 98.3%, but only the prevalence rates for hypospadias and "any FBDR defect" would be statistically significantly different from their current rates (Table 2, Figure 3). Lastly, improving the FBDR's timeliness a full year, which requires restriction to only 4 quarters of hospital discharge data, would reduce overall completeness more significantly, to 95.1%. Again, there was variation across specific defects, although less than that observed for reductions in follow-up time, with completeness for gastroschisis again being impacted least by data restriction (99.3% complete with data restriction from 8 to 4 quarters, Figure 3).

Table 3 represents the impact of scenarios that signify the most profound restrictions to both follow-up (from 1 year to the birth hospitalization) and data availability (from 8 quarters to 4 quarters) on the proportion of FBDR cases

Figure 3. The Effect of Data Availability on the Proportion of Cases Captured by the Florida Birth Defects Registry, by Defect Category, 2006–2011



Y-axis: Birth defect category.

X-axis: Proportion of cases missed.

Defect categories are sorted by the proportion of cases captured by restricting hospital discharge data availability to 1 year, relative to cases captured by the current FBDR (which incorporates 2 years of discharge data). For a given defect, each color represents the additional cases lost, relative to the previous restriction in data availability. For all analyses, infants were unduplicated at the level of the defect; however, an infant with multiple defects considered in this study will be included in more than one defect-specific analysis.

FBDR, Florida Birth Defects Registry.

that would have been missed for major defect groups, by selected demographic and perinatal characteristics. When considering all defects considered in this study collectively, women less than 20 years old, women without private insurance, women with inadequate or no prenatal care, and male infants, were subgroups that were most impacted by both restrictions on follow-up time and the amount of data used to create the FBDR. The biggest disparity observed was among women of different age categories, with the proportion of cases missed for women less than 20, compared to those 40 years and older, 2.2 and 1.6 times higher for follow-up restriction and data availability, respectively. We also observed a consistent increase in the proportion of cases missed with progressively higher gestational ages and birth weights. The most consistent finding across other major defect groups investigated (orofacial clefts, NTDs, and CCHDs) was that vaginal deliveries were more affected (higher proportion of cases missed) than cesarean section by follow-up and data restrictions (Table 3). The findings for other sociodemographic and perinatal characteristics were inconsistent, depending on the type of restriction and the defect group under study.

Discussion

The primary goal of this study was to evaluate whether a more timely registry, one in which lag time would be reduced by using less data to compile the FBDR, would suffer in its completeness. Our findings were extremely encouraging. Although there is variation by defect, and the impact depends on the amount of data used, we consistently observed that 6–9 month improvements in timeliness were achievable with a minimal sacrifice in completeness (0.6–1.7%). Of the 44 birth defects included in this study, only hypospadias would have a rate statistically significantly different from that reported in the current FBDR (32.59 vs 33.79 per 10,000 live births) if the registry were compiled 9 months earlier (which cuts current lag time in half) using only 5 total quarters of hospital discharge data. In this scenario, assuming a relatively consistent rate of live births throughout the year, each live birth would be followed for at least 3 months, and 75%, 50%, and 25% of all infants would be followed for 6, 9, and 12 months, respectively. Therefore, completeness remains high despite data restriction because infants are still being tracked long enough to detect nearly all defects that will be diagnosed in the first

Table 3. The Effect of Different Periods of Follow-up and Data Availability on the Proportion of Cases Missed for Selected Defects Reported by the Florida Birth Defects Registry, by Demographic and Perinatal Characteristics, 2006–2011

Characteristic	*Proportion (%) of Cases Currently Captured by the FBDR that Would be Missed under the Specified Scenario*							
	Orofacial Clefts[a]		Neural Tube Defects[a]		Critical Congenital Heart Defects[a]		Any FBDR Defect[a]	
	Follow-up[b]	Data Availability[c]	Follow-up[b]	Data Availability[c]	Follow-up[b]	Data Availability[c]	Follow-up[b]	Data Availability[c]
Overall	13.2	6.2	19.7	13.2	6.2	19.7	25.1	4.9
Maternal age (in years)							***	**
<20	17.6	7.3	21.0	17.6	7.3	21.0	32.4	5.3
20-29	12.5	6.0	20.2	12.5	6.0	20.2	28.1	5.4
30-39	12.9	5.9	19.0	12.9	5.9	19.0	19.6	4.4
≥40	14.0	8.8	12.5	14.0	8.8	12.5	14.6	3.3
Maternal race/ethnicity	**	**		**	**		***	
NH-White	11.4	4.4	20.2	11.4	4.4	20.2	26.7	4.8
NH-Black	9.7	6.8	16.4	9.7	6.8	16.4	22.2	5.4
Hispanic	19.9	9.8	20.9	19.9	9.8	20.9	25.2	5.0
Other	11.9	7.5	29.4	11.9	7.5	29.4	18.6	4.4
Principal payer for delivery	***	**		***	**		***	***
Medicaid	12.7	6.1	21.4	12.7	6.1	21.4	29.7	5.6
Private Insurance	10.7	5.0	18.2	10.7	5.0	18.2	19.5	4.0
Self-pay	25.4	12.3	17.8	25.4	12.3	17.8	24.2	6.2
Other	32.0	12.0	9.1	32.0	12.0	9.1	30.7	6.6
Adequacy of prenatal care							***	**
Adequate plus	14.7	6.2	18.2	14.7	6.2	18.2	23.1	4.6
Intermediate	12.9	6.8	22.6	12.9	6.8	22.6	27.8	5.4
Inadequate or none	9.1	4.3	29.4	9.1	4.3	29.4	29.3	5.8
Method of delivery	**	**	**	**	**	**	***	***
Cesarean section	10.1	4.4	16.4	10.1	4.4	16.4	20.7	4.1
Vaginal	15.8	7.6	27.0	15.8	7.6	27.0	29.3	5.8
Gestational age (in weeks)							***	**
VPTB (20-31)	20.5	6.4	17.6	20.5	6.4	17.6	15.9	4.6
PTB (32-36)	11.5	6.2	21.2	11.5	6.2	21.2	20.2	4.0
Term (37-44)	13.1	6.2	19.4	13.1	6.2	19.4	27.1	5.2
Birth weight (in grams)							***	**
VLBW (125-1500)	17.8	5.5	16.7	17.8	5.5	16.7	13.6	4.4
LBW (1500-2500)	13.8	7.9	16.5	13.8	7.9	16.5	16.5	3.8
Normal (2500-6000)	12.9	5.9	20.8	12.9	5.9	20.8	27.7	5.2
Plurality	*			*			***	
Singleton	12.9	6.1	19.1	12.9	6.1	19.1	25.3	4.9
Multiple	23.9	8.7	35.3	23.9	8.7	35.3	19.7	5.5
Infant sex							***	***
Male	12.2	6.3	18.8	12.2	6.3	18.8	28.0	5.4
Female	14.4	6.0	20.5	14.4	6.0	20.5	20.3	4.2

FBDR, Florida Birth Defects Registry; NH, non-Hispanic; PTB, preterm birth; VPTB, very preterm birth.

*$P < .05$; **$P < .01$; ***$P < .0001$; P values calculated from a chi-square test of statistical independence or a Fisher's exact test used to compare the proportion of cases missed across levels of each characteristic. For a given characteristic, only proportions within each column (a hypothetical scenario) are being compared.

[a]See Appendix A for a description of the defects included in each composite defect category. For all analyses, infants were unduplicated at the level of the defect; however, an infant with multiple defects considered in this study will be included in more than 1 defect-specific analysis.

[b]Values represent the proportion of cases missed in each subgroup by restricting follow-up to the duration of the birth hospitalization, relative to cases captured by the current FBDR (which incorporates a 1-year follow-up time period)

[c]Values represent the proportion of cases missed in each subgroup by restricting hospital discharge data availability to 1 year, relative to cases captured by the current FBDR (which incorporates 2 years of discharge data)

year of life. It is also important to restate that we restricted our investigation to hospital discharge data only, since those were the only sources in which we were able to determine the timing of each encounter. Other data sources—CMS data sets from 2006–2008 and infant death certificates from 2009–2011—are useful in identifying cases not identified in hospital discharge data.[12] Therefore, this study overestimates, albeit slightly, the decrease in completeness that would be conferred by improving the FBDR's timeliness.

The results of this study also demonstrate that the FBDR's completeness of ascertainment would be reduced by shortening the length of follow-up equally for each infant. This is different from the previous example of data restriction, which would result in different periods of follow-up for infants depending on when they are born during the calendar year. Compared to the current case definition (1 year of follow-up), the FBDR would capture 84% of infants with restriction of follow-up to just 1 month. There was considerable variability across anomaly types; defects with obvious physical manifestations present at birth—such as gastroschisis, clubfoot, bladder exstrophy, anencephaly, hypospadias—were least impacted by reducing follow-up time. These defects are identified during the birth hospitalization; therefore, only those instances in which the birth hospitalization lacked sufficient information to link the record to the birth certificate, or in which a coding error was made, would have failed to capture the defect. Conversely, completeness was reduced significantly with restrictions in follow-up for defects such as pyloric stenosis and biliary atresia, whose diagnosis is often made following clinical presentation for symptoms several weeks after birth.[21-24]

Our study also found that the impact of improving timeliness on the FBDR's current completeness of ascertainment varied according to a number of demographic and perinatal characteristics. Data restriction reduced overall completeness more in infants born to younger mothers, mothers without private insurance, term infants, and normal weight infants. These differences were likely due to a combination of factors including the distribution of defects, differential data linkage rates,[19] and characteristics of the birth hospitalization within each population subgroup. For example, infants born preterm, low birth weight, by cesarean section, or with other complications may have longer lengths of stay during their birth hospitalization. Increased utilization of medical services may increase the likelihood of diagnosis of birth defects relative to uncomplicated births. Therefore, restriction to only the birth hospitalization for case ascertainment would impact ascertainment among these sicker infants to a smaller degree.

Our study is not without limitations. First, the FBDR relies on ICD-9-CM codes to identify cases of birth defects, and those codes reside in administrative data sources not initially created for the purposes of establishing a birth defects registry. To correctly identify a defect, the ICD-9-CM code depends not only on an accurate diagnosis, but interpretation of the diagnostic write-up, translation into the correct diagnosis code, and entry of that code into the hospital database. Each step is subject to human error, and suboptimal accuracy in passive surveillance systems can be expected.[25-28] A statewide case confirmation protocol (eg, medical record review) for all defects included in this study (over 144,000) was not feasible. Thus, although we investigate the impact of different periods of follow-up and data availability/use on completeness, we are unable to jointly assess the effect on overall and defect-specific accuracy. Second, the FBDR captures birth defects among live-born infants only; it does not include spontaneous and elective terminations or fetal deaths. Although this does not affect the relative comparisons used in this study to evaluate the interplay between timeliness and completeness, we are unable to present a complete picture of the true incidence of birth defects. Last, our investigation does not cover the entire gamut of birth defects; we exclude defects such as atrial septal defects and microcephalus due to concerns with accuracy of discharge data, and other minor defects including lipomas and hemangiomas. However, our study focuses on 44 defects from all body systems which have been included in annual reports (since 2000) from the National Birth Defects Prevention Network that contain population-based data from state programs.[9]

Efforts to enhance data quality through the assessment of timeliness and completeness indicators are not unique to birth defects surveillance programs. Registries for cancer, communicable diseases, occupational illness, injuries, adverse drug reactions, and hospital-acquired infections around the world have explored a myriad of methodological and procedural changes to improve timeliness without sacrificing the comprehensiveness of their surveillance systems.[29-42] However, this study contributes to the surveillance methods literature by exploring scenarios that reflect possible tradeoffs between timeliness and completeness in a population-based, passive surveillance system. In Florida, these results are being shared with members of the FBDR consortium, which includes representatives from FDOH, data owners (AHCA and the Bureau of Vital Statistics), academic partners from the University of South Florida, and other stakeholders. Therefore, beginning in 2015, Florida plans to construct a provisional FBDR, using a restricted linkage of case ascertainment data sources and improving the time lag by 6–9 months, followed by release of a final FBDR built using the full extent of data. This strategy mirrors those implemented in state and national reporting of other public health statistics (eg, births, marriages, divorces, and deaths) and should increase Florida's capacity for providing more current data, responding to questions from medical and public health providers, local health departments, and the public at large. Other programs, particularly those with similar passive case ascertainment protocols, can use our findings to consider a more timely release of registry data, or to design similar investigations of their own.

Acknowledgments

The authors would like to acknowledge the following organizations and individuals for their contribution to this project: Marie Bailey, MA, MSW for her expertise in data linkage; members of the Florida Birth Defects Registry consortium for their ongoing input and guidance; and staff of the Florida Department of Health and the Agency for

Health Care Administration for providing access to these data and their ongoing support of birth defects surveillance in Florida.

References

1. Centers for Disease Control and Prevention. Update on overall prevalence of major birth defects--Atlanta, Georgia, 1978-2005. *MMWR Morb Mortal Wkly Rep*. 2008;57(1):1-5.
2. Facts about birth defects. Centers for Disease Control and Prevention website. **http://www.cdc.gov/ncbddd/birthdefects/facts.html**. Updated October 20, 2014. Accessed November 30, 2014.
3. Heron M. Deaths: leading causes for 2010. *Natl Vital Stat Rep*. 2013;62(6):1-96
4. Mai CT, Kirby RS, Correa A, Rosenberg D, Petros M, Fagen MC. Public health practice of population-based birth defects surveillance programs in the United States [published online ahead of print April 22, 2015]. *J Public Health Manag Pract*. doi: 10.1097/PHH.0000000000000221.
5. Sever LE, ed. *Guidelines for Conducting Birth Defects Surveillance*. Atlanta, GA: National Birth Defects Prevention Network, Inc; 2004.
6. Cain MA, Salemi JL, Paul Tanner J, et al. Perinatal outcomes and hospital costs in gastroschisis based on gestational age at delivery. *Obstet Gynecol*. 2014;124(3):543-550.
7. Dawson AL, Cassell CH, Oster ME, et al. Hospitalizations and associated costs in a population-based study of children with down syndrome born in Florida. *Birth Defects Res A Clin Mol Teratol*. 2014;100(11):826-836.
8. Dawson AL, Cassell CH, Riehle-Colarusso T, et al. Factors associated with late detection of critical congenital heart disease in newborns. *Pediatrics*. 2013;132(3):e604-e611.
9. Mai CT, Kucik JE, Isenburg J, et al. Selected birth defects data from population-based birth defects surveillance programs in the United States, 2006 to 2010: featuring trisomy conditions. *Birth Defects Res A Clin Mol Teratol*. 2013;97(11):709-725.
10. Radcliff E, Cassell CH, Tanner JP, et al. Hospital use, associated costs, and payer status for infants born with spina bifida. *Birth Defects Res A Clin Mol Teratol*. 2012;94(12):1044-1053.
11. Salemi JL, Pierre M, Tanner JP, et al. Maternal nativity as a risk factor for gastroschisis: a population-based study. *Birth Defects Res A Clin Mol Teratol*. 2009;85(11):890-896.
12. Salemi JL, Tanner JP, Block S, et al. The relative contribution of data sources to a birth defects registry utilizing passive multisource ascertainment methods: does a smaller birth defects case ascertainment net lead to overall or disproportionate loss? *J Registry Manage*. 2011;38(1):30-38.
13. Salemi JL, Tanner JP, Kennedy S, et al. A comparison of two surveillance strategies for selected birth defects in Florida. *Public Health Rep*. 2012;127(4):391-400.
14. Tanner JP, Salemi JL, Hauser KW, Correia JA, Watkins SM, Kirby RS. Birth defects surveillance in Florida: infant death certificates as a case ascertainment source. *Birth Defects Res A Clin Mol Teratol*. 2010;88(12):1017-1022.
15. Salemi JL, Tanner JP, Sampat D, et al. The accuracy of hospital discharge diagnosis codes for major birth defects: evaluation of a statewide registry with passive case ascertainment [published online ahead of print June 29, 2015]. *J Public Health Manag Pract*. doi: 10.1097/PHH.0000000000000291.
16. German RR, Lee LM, Horan JM, et al. Updated guidelines for evaluating public health surveillance systems: recommendations from the Guidelines Working Group. *MMWR Recomm Rep*. 2001;50(RR-13):1-35; quiz CE31-37.
17. Lee LM, Teutsch SM, Thacker SB, Louis MES. Principles and Practice of Public Health Surveillance. 3rd ed. New York, NY: Oxford University Press; 2010.
18. Salemi JL, Hauser KW, Tanner JP, et al. Developing a database management system to support birth defects surveillance in Florida. *J Registry Manage*. 2010;37(1):10-15.
19. Salemi JL, Tanner JP, Bailey M, Mbah AK, Salihu HM. Creation and evaluation of a multi-layered maternal and child health database for comparative effectiveness research. *J Registry Manage*. 2013;40(1):14-28.
20. Alexander GR, Cornely DA. Prenatal care utilization: its measurement and relationship to pregnancy outcome. *Am J Prev Med*. 1987;3(5):243-253.
21. Mogul D, Zhou M, Intihar P, Schwarz K, Frick K. Cost-effective analysis of screening for biliary atresia with the stool color card. *J Pediatr Gastroenterol Nutr*. 2015;60(1):91-98.
22. Namini FT, Raisolsadat SM, Omid F, Mirzade M. Is hypertrophic pyloric stenosis a secondary disease? *Afr J Paediatr Surg*. 2013;10(1):46-49.
23. Ramonet M, Ciocca M, Alvarez F. Biliary atresia: a severe illness [in Spanish]. *Arch Argent Pediatr*. 2014;112(6):542-547.
24. Ranells JD, Carver JD, Kirby RS. Infantile hypertrophic pyloric stenosis: epidemiology, genetics, and clinical update. *Adv Pediatr*. 2011;58(1):195-206.
25. Boulet SL, Correa-Villasenor A, Hsia J, Atrash H. Feasibility of using the national hospital discharge survey to estimate the prevalence of selected birth defects. *Birth Defects Res A Clin Mol Teratol*. 2006;76(11):757-761.
26. Callif-Daley FA, Huether CA, Edmonds LD. Evaluating false positives in two hospital discharge data sets of the Birth Defects Monitoring Program. *Public Health Rep*. 1995;110(2):154-160.
27. Cronk CE, Malloy ME, Pelech AN, et al. Completeness of state administrative databases for surveillance of congenital heart disease. *Birth Defects Res A Clin Mol Teratol*. 2003;67(9):597-603.
28. Hexter AC, Harris JA. Bias in congenital malformations information from the birth certificate. *Teratology*. 1991;44(2):177-180.
29. Bennett S, Grenier D, Medaglia A. The Canadian Paediatric Surveillance Program: a framework for the timely data collection on head injury secondary to suspected child maltreatment. *Am J Prev Med*. 2008;34(suppl 4):S140-S142.
30. Books SJ. Regarding "the completeness, validity, and timeliness of AIDS surveillance data". *Ann Epidemiol*. 2002;12(4):284.
31. Chu A, Savage R, Whelan M, et al. Assessing the relative timeliness of Ontario's syndromic surveillance systems for early detection of the 2009 influenza H1N1 pandemic waves. *Can J Public Health*. 2013;104(4):340-347.
32. Hedberg CW, Greenblatt JF, Matyas BT, et al. Timeliness of enteric disease surveillance in 6 US states. *Emerg Infect Dis*. 2008;14(2):311-313.
33. Huaman MA, Araujo-Castillo RV, Soto G, et al. Impact of two interventions on timeliness and data quality of an electronic disease surveillance system in a resource limited setting (Peru): a prospective evaluation. *BMC Med Inform Decis Mak*. 2009;9:16.
34. Jajosky RA, Groseclose SL. Evaluation of reporting timeliness of public health surveillance systems for infectious diseases. *BMC Public Health*. 2004;4:29.
35. Johnson MG, Williams J, Lee A, Bradley KK. Completeness and timeliness of electronic vs conventional laboratory reporting for communicable disease surveillance—Oklahoma, 2011. *Public Health Rep*. 2014;129(3):261-266.
36. Lo HY, Yang SL, Chou P, Chuang JH, Chiang CY. Completeness and timeliness of tuberculosis notification in Taiwan. *BMC Public Health*. 2011;11:915.
37. Nicolay N, Garvey P, Delappe N, Cormican M, McKeown P. Completeness and timeliness of Salmonella notifications in Ireland in 2008: a cross sectional study. *BMC Public Health*. 2010;10:568.
38. Overhage JM, Grannis S, McDonald CJ. A comparison of the completeness and timeliness of automated electronic laboratory reporting and spontaneous reporting of notifiable conditions. *Am J Public Health*. 2008;98(2):344-350.
39. Samoff E, Fangman MT, Fleischauer AT, Waller AE, Macdonald PD. Improvements in timeliness resulting from implementation of electronic laboratory reporting and an electronic disease surveillance system. *Public Health Rep*. 2013;128(5):393-398.
40. Sigurdardottir LG, Jonasson JG, Stefansdottir S, et al. Data quality at the Icelandic Cancer Registry: comparability, validity, timeliness and completeness. *Acta Oncol*. 2012;51(7):880-889.
41. Yoo HS, Park O, Park HK, et al. Timeliness of national notifiable diseases surveillance system in Korea: a cross-sectional study. *BMC Public Health*. 2009;9:93.
42. Zanetti R, Schmidtmann I, Sacchetto L, et al. Completeness and timeliness: Cancer registries could/should improve their performance. *Eur J Cancer*. 2014.

Appendix A. ICD-9-CM Diagnosis Codes Used To Identify Individual Birth Defects and Defect Categories Included in This Study			
Birth Defect	*ICD-9-CM Codes*[a]	*Birth Defect*	*ICD-9-CM Codes*[a]
Anencephaly	740.0, 740.1	Hypospadias	752.61
Aniridia	743.45	Interrupted aortic arch	747.11
Anophthalmia/microphthalmia	743.0x, 743.1x	Limb deficiencies (reduction defects)	755.2x, 755.3x, 755.4x
Anotia/microtia	744.01, 744.23	Pulmonary valve atresia and stenosis	746.01, 746.02
Aortic valve stenosis	746.3	Pyloric stenosis	750.5
Biliary atresia	751.61	Rectal and large intestinal atresia/ stenosis	751.2
Bladder exstrophy	753.5	Renal agenesis/hypoplasia	753.0
Choanal atresia	748.0	Single ventricle	745.3
Cloacal exstrophy	751.5	Small intestinal atresia/stenosis	751.1
Clubfoot	754.51, 754.70	Spina bifida without anencephalus	741.xx w/o 740.0, 740.1
Coarctation of the aorta	747.10	Tetralogy of Fallot	745.2
Common truncus	745.0	Total anomalous pulmonary venous connection	747.41
Congenital cataract	743.30 – 743.34	Transposition of the great arteries	745.10, 745.12, 745.19
Congenital posterior urethral valves	753.6	Tricuspid valve atresia and stenosis	746.1
Deletion 22 q11.2	758.32	Trisomy 13	758.1
Diaphragmatic hernia	756.6	Trisomy 18	758.2
Double outlet right ventricle	745.11	Trisomy 21	758.0
Ebstein anomaly	746.2	Turner syndrome	758.6
Encephalocele	742.0	Ventricular septal defect	745.4
Endocardial cushion defect	745.6x	Any critical congenital heart defect	745.0, 745.10, 745.11, 745.2, 745.3, 746.01, 746.1, 746.2, 746.7, 747.1x, 747.41
Esophageal atresia/ tracheoesophageal fistula	750.3	Any congenital heart defect	745.0, 745.1x, 745.2, 745.3, 745.4, 745.6x, 746.01, 746.02, 746.1, 746.2, 746.3, 746.7, 747.1x, 747.41
Gastroschisis	756.79 w/ 54.71[b] or 756.73	Any neural tube defect	740.0, 740.1, 741.xx, 742.0
Holoprosencephaly	742.2	Any orofacial cleft	749.xx
Hydrocephalus without spina bifida	742.3 w/o 741.xx	Any FBDR defect	*See footnote*[c]
Hypoplastic left heart syndrome	746.7		

FBDR, Florida Birth Defects Registry; ICD-9-CM, International Classification of Diseases, Ninth Edition.

[a]Presence of 1 or more of the listed codes serves as positive indication of the defect. Similarly, presence of 1 or more of the listed codes following "w/o" indicates absence of the defect regardless of other listed codes. An "x" indicates that all subcodes with the listed code prefix are part of the defect definition.

[b]Beginning October 1, 2009, gastroschisis is identified exclusively by a single ICD-9-CM diagnosis code (756.73). Prior to that, cases of gastroschisis were identified using the presence of both the non-specific 756.79 ICD-9-CM diagnosis code ("other congenital anomalies of abdominal wall") and the 54.71 ICD-9-CM *procedure* code indicating repair of gastroschisis.[11]

[c]The "any FBDR defect" category consists of all of the defects listed in the appendix.

Original Article

Renal Cancer Patients with Unknown Ethnicity in Cancer Registry Data: Comparisons to Patients with Known Ethnicity

Jie Lin, PhD, MPH[a]; Elizabeth Butts, MPH, CTR[b]; Paul D. Rockswold, MD, MPH, FAAFP[b]; Craig D. Shriver, MD[a,c]; Kangmin Zhu, MD, PhD[a,c]

Abstract: Background: Information on ethnicity is important for health disparity research and health service planning. However, information on ethnicity is often incomplete in large routine databases such as cancer registries. This study aimed to compare survival status and other characteristics between cancer patients with and without information on Hispanic ethnicity in cancer registry data. Methods: The study included 2,426 patients with clear cell renal cell carcinoma (RCC) diagnosed between 1988 and 2004 and identified from the US Department of Defense (DoD)'s Automated Central Tumor Registry (ACTUR) database. There were 1,353 non-Hispanic patients, 134 Hispanic patients, and 939 patients with unknown ethnicity. Patients were followed through death, date of last contact, or censored on December 31, 2007. Results: Patients with unknown ethnicity exhibited significantly shorter survival than non-Hispanic or Hispanic patients (Log Rank $P < .0001$). Further analysis showed that compared to patients with known ethnicity, patients with unknown ethnicity were more likely to have advanced tumor stage at diagnosis and more likely to have missing information on tumor grade, size, and some demographic characteristics. After adjustment for demographic, tumor and treatment variables, patients with unknown ethnicity still exhibited significantly higher mortality than non-Hispanic patients (hazard ratio [HR], 1.69; 95% CI, 1.48–1.92), while Hispanic patients were not different from non-Hispanic patients (HR, 0.95; 95% CI, 0.71–1.28). The shorter survival in the unknown ethnicity group was consistently observed in subgroups by age, race, stage, grade, and surgical treatment, suggesting factors other than those investigated in the current study may play a role in the survival differences between patients with and without information on Hispanic ethnicity. Implications: The poor survival of patients with unknown ethnicity in ACTUR warrants further research to elucidate missing mechanisms. Improvement in collection of data by reaching out for more engagement of patients, clinicians and registrars and increasing patient-provider interactions is needed.

Key words: *cancer registry, renal cell carcinoma, survival, unknown ethnicity*

Introduction

Race and ethnicity data are essential for health disparity research, which provides evidence for policy-making and service planning in reducing racial and ethnic disparity. Large routine health data sets such as cancer registry data often contain information on race and ethnicity, providing resources for research on racial and ethnic disparities. However, missing information on race and/or ethnicity is common in such data sets, which limits the use of the data.[1,2] Furthermore, missing mechanisms have not been adequately addressed and investigated by researchers.[3,4] Therefore, the effects of missing ethnicity on research results are unclear.

Understanding of missing mechanisms, such as why data are unknown in some patients and whether the missing data are random or not, is important to the interpretation of results and development of imputing algorithms.[2,4-9] However, few previous studies investigated why data on race or ethnicity are missing for some patients but not others. A recent study, which did not distinguish race and ethnicity, found that the breast cancer screening rates were significantly lower among women with missing race/ethnicity as compared to women with known race/ethnicity, including minorities.[10] The same study found that women with missing race/ethnicity data had fewer routine medical visits and were less likely to have an identified primary care physician as compared to women with known race/ethnicity,[10] suggesting health care–seeking behavior might be the underlying reason for missing data. These observations suggest the significance of understanding

[a]John P. Murtha Cancer Center, Walter Reed National Military Medical Center, Bethesda, Maryland. [b]Health Analysis, Navy and Marine Corps Public Health Center, Portsmouth, Virginia. [c]Uniformed Services University, Bethesda, Maryland.

Address correspondence to Kangmin Zhu, MD, PhD or Jie Lin, PhD, MPH; Division of Military Epidemiology and Population Sciences, John P. Murtha Cancer Center, Walter Reed National Military Medical Center, 11300 Rockville Pike, Suite 1120, Rockville, MD 20852. Telephone: (301) 816-4786 (Dr. Zhu), 301-816-4787 (Dr. Lin). Fax: (301) 881-7197. Email: kzhu@murthacancercenter.org (Dr. Zhu) or jlin@murthacancercenter.org (Dr. Lin).

The views expressed in this article are those of the authors and do not necessarily reflect the official policy or position of the Department of the Navy, Army, Department of Defense (DoD), nor the US Government. Nothing in the presentation implies any Federal/DoD endorsement.

This project was supported by John P. Murtha Cancer Center, Walter Reed National Military Medical Center via the Uniformed Services University of the Health Sciences under the auspices of the Henry M. Jackson Foundation for the Advancement of Military Medicine. The authors thank the Joint Pathology Center (formerly Armed Forces Institute of Pathology) for providing the data.

missing mechanisms and better characterizing patients with missing race/ethnicity in large routine data sets.

While race and ethnicity are sometimes undistinguished, they have different definitions conceptually. Race usually refers to biological inheritance and phenotypic traits such as skin color and facial features, but ethnicity is more culture-related and is characterized by distinctive social and cultural traditions as well as biologic heritage.[11-13] The US Census Bureau has distinguished race and ethnicity since 1990.[14-16] Two ethnicity categories, Hispanic and non-Hispanic, are used in the Census Bureau surveys for federally supported programs following the guidance of the Office of Management and Budget (OMB).[14,15] Since ethnicity reflects social and cultural features that may be modifiable to improve health-related behaviors,[17,18] investigation of outcomes by ethnic status including unknown ethnicity is important for identifying specific groups without the information and for intervention. To date, there has been little research comparing individuals with and without data on ethnicity among cancer patients.

As part of an ongoing research on survival among patients with renal cell carcinoma (RCC) identified from the Department of Defense's (DoD) Automated Tumor Registry (ACTUR), we observed a high percentage of patients with unknown Hispanic ethnicity and a significantly worse survival for the group compared to those with known ethnicity. The current study aimed to characterize patients with unknown Hispanic ethnicity in survival as compared to those with known ethnicity and assess factors related to differences in survival including demographic variables, tumor characteristics, and receipt of treatments.

Methods

Sources of Data

The data source was described previously.[19] Briefly, data on patients diagnosed with RCC between 1988–2004 were obtained from the ACTUR, a clinical tracking system for cancer patients who were diagnosed or received cancer treatment at military treatment facilities. The facilities are required to report cancer data to ACTUR on all DoD beneficiaries with cancer, including active-duty members, retirees, and their dependents. The ACTUR data are reviewed by specialized registrars to verify diagnosis. ACTUR is compliant with the North American Association of Central Cancer Registries (NAACCR) uniform data standards for cancer registries.[20] The ACTUR data contain information on age at diagnosis, sex, race, ethnicity, marital status, active duty status, military service branch, tumor stage, tumor grade, tumor size, cancer treatment (eg, surgery, chemotherapy, radiation), tumor recurrence, vital status, and date of last contact or death.

Regarding ethnicity, ACTUR has a Spanish/Hispanic origin data field that has a code for non-Hispanic patients and codes for different Hispanic origins (Mexican, Puerto Rican, Cuban, South or Central America [except Brazil], other specified Spanish/Hispanic origin [includes European], other nonspecified Spanish/Hispanic origins, and Spanish surname only). Ethnicity was coded as "unknown" if ethnicity information was not found in medical records, death certificates, or other sources that define Hispanic origin. In our data analysis, patients with different Hispanic origins were grouped into "Hispanic." As a result, there were 3 study groups: non-Hispanic, Hispanic, and unknown ethnicity. This study was based on the nonidentifiable ACTUR data approved for our research by the institutional review boards of the former US Military Cancer Institute, Walter Reed National Military Medical Center, and the former Armed Forces Institute of Pathology.

Study Patients

Patients included in the study had been diagnosed with histologically confirmed primary renal cell carcinoma (RCC) with clear cell histology between January 1, 1988 and December 31, 2004. Clear cell type constitutes over 85% of all RCC.[21,22] The diagnosis was defined by the tumor site code (C64.9) and morphology codes (8310–8312) of the International Classification of Diseases for Oncology, third edition (ICD-O-3).[23] Patients with a history of cancers other than RCC were excluded from the study to minimize the potential effect of multiple cancers on survival. A total of 2,426 patients were included in the final analysis.

Patients were followed up through death, date of last contact, or censored on December 31, 2007. The observed survival time was calculated as the difference between date of diagnosis and date of death for patients who died during the study period. For patients who did not die during the study period, survival time was censored at the date of last contact or December 31, 2007. The study outcome was all-cause mortality. Kaplan–Meier survival curves and Log-rank test were used to assess whether survival differed between unknown ethnicity, non-Hispanic, and Hispanic groups. We then compared the groups in demographic variables, tumor characteristics, and receipt of treatments to investigate whether these factors were associated with unknown ethnicity status using the chi-square test. Finally, we assessed whether the differences in survival between the unknown ethnicity and known ethnicity groups remained in the Cox regression model adjusting for age, gender, race, active duty status, marital status, tumor stage, grade, size, receipt of surgery, chemotherapy, radiation therapy, and recurrence. We further conducted Cox regression analysis stratified by demographic characteristics, tumor stage, tumor grade, and treatments (surgery, chemotherapy, and radiation therapy). Hazard ratios (HRs) and their 95% confidence intervals (95% CIs) associated with ethnicity were calculated. Statistical analyses were conducted using the SAS software version 9.3.0 (SAS Institute, Inc).

Results

There were 1,353 non-Hispanic patients, 134 Hispanic patients, and 939 patients with unknown ethnicity, representing 55.8%, 5.5% and 38.7% of the study patients, respectively. During follow-up, 529, 50, and 609 non-Hispanic, Hispanic, and unknown ethnicity patients died, respectively. The Kaplan–Meier analysis showed significant worse survival in patients with unknown ethnicity than non-Hispanic or Hispanic groups (Log Rank $P < .0001$)

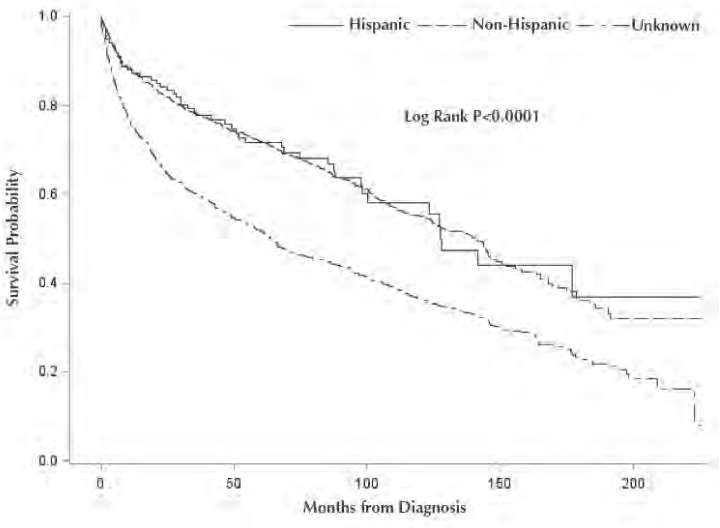
Table 1. Demographic Variables, Tumor Characteristics and Treatments by Ethnicity among Patients Diagnosed with Renal Cell Carcinoma in the US Department of Defense Cancer Registry (1988–2004)

Variables	*Non-Hispanic, n (%)*	*Hispanic, n (%)*	*Unknown Ethnicity, n (%)*	P *Value (non-Hispanic vs unknown)*	P *Value (Hispanic vs unknown)*
	n = 1,353	**n = 134**	**n = 939**		
Age(y), by quartile				.2594	.0002
<50	310 (22.9)	49 (36.6)	198 (21.1)		
50–59	310 (22.9)	29 (21.6)	248 (26.4)		
60–66	349 (25.8)	34 (25.4)	230 (24.5)		
≥67	384 (28.4)	22 (16.4)	263 (28.0)		
Race				.001	<.0001
White	1106 (81.7)	134 (100.00)	816 (86.9)		
Black	247 (18.3)	0 (0.00)	123 (13.1)		
Sex				.2508	.1307
Male	944 (69.8)	88 (65.7)	676 (72.0)		
Female	409 (30.2)	46 (34.3)	263 (28.0)		
Marital status				.0001	.0062
Never married	49 (3.62)	4 (3.0)	40 (4.3)		
Married	1078 (79.7)	114 (85.1)	713 (75.9)		
Separated	12 (0.9)	2 (1.5)	1 (0.1)		
Divorced	53 (3.9)	4 (3.0)	28 (3.0)		
Widowed	89 (6.6)	4 (3.0)	64 (6.8)		
Unknown	72 (5.3)	6 (4.5)	93 (9.9)		
Active duty status				.3108	.6425
Yes	152 (11.2)	15 (11.2)	93 (9.9)		
No	1201 (88.8)	119 (88.8)	846 (90.1)		
Sponsor service branch				<.0001	.6242
Army	498 (36.8)	51 (38.1)	346 (36.9)		
Navy	271 (20.0)	23 (17.2)	149 (15.9)		
Air Force	438 (32.4)	37 (27.6)	291 (33.1)		
Marines	60 (4.4)	7 (5.22)	29 (3.1)		
Coast Guard	13 (1.0)	0 (0.0)	9 (1.0)		
Unknown	73 (5.4)	16 (11.9)	115 (12.3)		
Tumor stage				<.0001	.2231
Localized	860 (63.6)	80 (59.7)	497 (52.9)		
Regional	192 (14.2)	22 (16.4)	169 (18.0)		
Distant	176 (13.0)	22 (16.4)	220 (23.4)		
Unknown	125 (9.2)	10 (7.5)	53 (5.6)		
Tumor grade				<.0001	<.0001
Well differentiated	159 (11.8)	10 (7.5)	108 (11.5)		
Moderately differentiated	357 (26.4)	37 (27.2)	122 (13.0)		
Poorly differentiated	192 (14.2)	27 (20.2)	84 (9.0)		
Undifferentiated	54 (4.0)	5 (3.7)	22 (2.3)		
Differentiation unknown	591 (43.7)	55 (41.0)	603 (64.2)		

Table 1, cont. Demographic Variables, Tumor Characteristics and Treatments by Ethnicity among Patients Diagnosed with Renal Cell Carcinoma in the US Department of Defense Cancer Registry (1988–2004)

Variables	*Non-Hispanic, n (%)*	*Hispanic, n (%)*	*Unknown Ethnicity, n (%)*	P *Value (non-Hispanic vs unknown)*	P *Value (Hispanic vs unknown)*
	n = 1,353	**n = 134**	**n = 939**		
Tumor size (mm), by quartiles				.0044	.7281
≤30	328 (24.2)	28 (20.9)	191 (20.3)		
31 to50	302 (22.3)	30 (22.4)	188 (20.0)		
51 to 80	287 (21.2)	28 (20.9)	210 (22.4)		
>80	231 (17.1)	26 (19.4)	156 (16.6)		
Unknown	205 (15.2)	22 (16.4)	194 (20.7)		
Surgery				<.0001	<.0001
No	136 (10.1)	16 (11.9)	185 (19.7)		
Yes	1201 (88.8)	118 (88.1)	734 (78.2)		
Unknown	16 (1.2)	0 (0.00)	20 (2.1)		
Chemotherapy				.0007	.4017
No	1281 (94.7)	129 (96.3)	876 (93.3)		
Yes	31 (2.3)	4 (3.0)	46 (4.9)		
Unknown	41 (3.0)	1 (0.8)	17 (1.8)		
Radiation therapy				<.0001	.1464
No	1240 (91.7)	126 (94.0)	830 (88.4)		
Yes	72 (5.3)	7 (5.2)	94 (10.0)		
Unknown	41 (3.0)	1 (0.8)	15 (1.6)		
Recurrence				<.0001	.0181
No	974 (72.0)	103 (76.9)	757 (80.6)		
Yes	168 (12.4)	18 (13.4)	121 (12.9)		
Never disease free	167 (12.3)	10 (7.5)	24 (2.6)		
Unknown	44 (3.3)	3 (2.2)	37 (3.9)		

Figure1. Kaplan–Meier Survival Curves by Ethnicity in Clear Cell Renal Cell Carcinoma Patients Diagnosed from 1988–2004 in the US Department of Defense Cancer Registry



(Figure 1). The worse survival of patients with unknown ethnicity was consistently observed in subgroups stratified by age, sex, race, and tumor stage (results not shown).

Table 1 shows the distributions of demographic, tumor, and treatment characteristics by ethnicity status. The distributions of age and sex were similar between patients with unknown ethnicity and non-Hispanic patients, while the Hispanic group tended to be younger at diagnosis. The unknown ethnicity group was more likely to be white (86.9%) than the non-Hispanic group (81.7%). Patients with unknown ethnicity were more likely to be diagnosed at distant tumor stage (23.4%), compared to non-Hispanic (13.0%) and Hispanic patients (16.4%). They also had the highest percentage of unknown status in terms of tumor grade, tumor size, marital status, and service branch. Regarding treatments, 19.7% of patients with unknown ethnicity did not receive surgery of any type, while 10.1% of non-Hispanic patients and 11.9% of Hispanic patients received no surgery, respectively. However, the percentage receiving chemotherapy was higher for patients with

Table 2. Hazard Ratios of Ethnicity Among Patients Diagnosed with Renal Cell Carcinoma in the US Department of Defense Cancer Registry (1988–2004)

Variables	*Ethnicity*	*Total Deaths/Total Patients*	*Multivariate Hazard Ratio**	*95% CI**
Overall	Non-Hispanic	529/1353	1.00 (Ref)	
	Hispanic	50/134	0.95	0.71 to 1.28
	Unknown Ethnicity	609/939	1.69	1.48 to 1.92
Race				
White	Non-Hispanic	449/1106	1.00 (Ref)	
	Hispanic	50/134	0.92	0.68 to 1.24
	Unknown Ethnicity	531/816	1.62	1.41 to 1.86
Black	Non-Hispanic	80/247	1.00 (Ref)	
	Hispanic	0/0	N/A	N/A
	Unknown Ethnicity	78/123	2.25	1.52 to 3.33
Age (Yr), by median				
<59	Non-Hispanic	177/620	1.00 (Ref)	
	Hispanic	25/78	1.25	0.81 to 1.93
	Unknown Ethnicity	226/446	1.91	1.52 to 2.40
≥59	Non-Hispanic	352/733	1.00 (Ref)	
	Hispanic	25/56	0.76	0.50 to 1.16
	Unknown Ethnicity	383/493	1.63	1.38 to 1.92
Sex				
Male	Non-Hispanic	387/944	1.00 (Ref)	
	Hispanic	36/88	0.92	0.65 to 1.31
	Unknown Ethnicity	448/676	1.72	1.48 to 2.00
Female	Non-Hispanic	142/409	1.00 (Ref)	
	Hispanic	14/46	1.44	0.80 to 2.59
	Unknown Ethnicity	161/263	1.69	1.29 to 2.22
Tumor Stage				
Localized	Non-Hispanic	242/860	1.00 (Ref)	
	Hispanic	18/80	1.05	0.64 to 1.72
	Unknown Ethnicity	241/497	1.77	1.46 to 2.15
Regional	Non-Hispanic	93/192	1.00 (Ref)	
	Hispanic	8/22	1.00	0.47 to 2.11
	Unknown Ethnicity	121/169	1.99	1.48 to 2.67
Distant	Non-Hispanic	158/176	1.00 (Ref)	
	Hispanic	21/22	0.97	0.60 to 1.55
	Unknown Ethnicity	216/220	1.29	0.97 to 1.72
Unknown	Non-Hispanic	36/125	1.00 (Ref)	
	Hispanic	3/10	1.92	0.45 to 8.26
	Unknown Ethnicity	31/53	2.68	1.30 to 5.50

Table 2, cont. Hazard Ratios of Ethnicity Among Patients Diagnosed with Renal Cell Carcinoma in the US Department of Defense Cancer Registry (1988–2004)

Variables	*Ethnicity*	*Total Deaths/Total Patients*	*Multivariate Hazard Ratio**	*95% CI**
Tumor Grade				
Well and moderately differentiated	Non-Hispanic	126/516	1.00 (Ref)	
	Hispanic	8/47	0.87	0.42 to 1.83
	Unknown Ethnicity	112/230	1.70	1.29 to 2.23
Poorly and undifferentiated	Non-Hispanic	124/246	1.00 (Ref)	
	Hispanic	14/32	0.57	0.31 to 1.05
	Unknown Ethnicity	79/106	1.38	1.00 to 1.91
Differentiation unknown	Non-Hispanic	279/591	1.00 (Ref)	
	Hispanic	28/55	1.29	0.86 to 1.94
	Unknown Ethnicity	418/603	1.81	1.52 to 2.17
Surgery				
Yes	Non-Hispanic	388/1201	1.00 (Ref)	
	Hispanic	34/118	0.77	0.54 to 1.11
	Unknown Ethnicity	412/734	1.82	1.58 to 2.11
No	Non-Hispanic	130/136	1.00 (Ref)	
	Hispanic	16/16	1.16	0.64 to 2.10
	Unknown Ethnicity	180/185	1.42	0.99 to 2.03
Unknown	Non-Hispanic	11/16	1.00 (Ref)	
	Hispanic	0/0	N/A	N/A
	Unknown Ethnicity	17/20	2.81	0.53 to 14.79
Chemotherapy				
Yes	Non-Hispanic	25/31	1.00 (ref.)	
	Hispanic	4/4	0.67	0.17 to 2.71
	Unknown Ethnicity	46/46	1.38	0.64 to 3.01
No	Non-Hispanic	478/1281	1.00 (ref.)	
	Hispanic	46/129	0.93	0.68 to 1.27
	Unknown Ethnicity	552/876	1.79	1.57 to 2.04
Unknown	Non-Hispanic	26/41	1.00 (ref.)	
	Hispanic	0/1	N/A	N/A
	Unknown Ethnicity	11/17	1.71	0.36 to 8.17
Radiation Therapy				
Yes	Non-Hispanic	63/72	1.00 (ref.)	
	Hispanic	7/7	1.27	0.53 to 3.04
	Unknown Ethnicity	92/94	1.50	0.91 to 2.46
No	Non-Hispanic	43/1240	1.00 (ref.)	
	Hispanic	43/126	0.86	0.62 to 1.19
	Unknown Ethnicity	508/830	1.74	1.51 to 1.99
Unknown	Non-Hispanic	23/41	1.00 (ref.)	
	Hispanic	0/1	N/A	N/A
	Unknown Ethnicity	32/57	0.59	0.99 to 21.39

* Unless stratified by the variable, adjusted by age, sex, race, marital status, active duty status, tumor stage, tumor grade, tumor size, receipt of surgery, chemotherapy, radiation therapy, and recurrence. HR, hazard ratio, N/A, not applicable.

unknown ethnicity (4.9%) than either non-Hispanic patients (2.3%) or Hispanic patients (3.0%). Similarly, the percentage of patients receiving radiation therapy was higher for those with unknown ethnicity (10.0%) than for non-Hispanic (5.3%) or Hispanic patients (5.2%). Also, patients with unknown ethnicity were more likely to have no recorded cancer recurrence (80.6%) than non-Hispanic (72.0%) or Hispanic (76.9%) patients.

After adjustment for demographic, tumor, and treatment variables, patients with unknown ethnicity exhibited a higher HR compared to non-Hispanic patients (HR, 1.69; 95% CI, 1.48–1.92), while Hispanic patients were similar to non-Hispanic patients (HR, 0.95; 95% CI, 0.71–1.28) (Table 2). The higher HR for the patients with unknown ethnicity compared to non-Hispanic patients was consistently present regardless of race, age, sex, tumor stage, tumor grade, and receipt of surgery, chemotherapy or radiation therapy in stratified analyses (Table 2). Similar to the overall analysis, no survival disadvantage was observed among patients of Hispanic origin compared to non-Hispanic patients.

Discussion

This study showed that renal cancer patients with unknown Hispanic ethnicity experienced significantly worse survival compared to both non-Hispanic and Hispanic patients in the ACTUR data. Further analyses showed that they were more likely to be diagnosed at a more advanced stage than patients with known ethnicity. In addition, patients with unknown ethnicity were more likely to have missing information on tumor grade, tumor size, marital status, and service branch. Finally, the poor survival in this group was consistently observed regardless age, sex, race, tumor stage, tumor grade, or receipt of surgery.

Few previous studies have compared characteristics between patients with and without information on Hispanic ethnicity. Two studies on survival in breast cancer patients, which did not distinguish race and ethnicity, reported survival difference between the unknown racial group and the known racial groups.[24,25] While 1 study found a worse survival for the unknown racial group than the known ethnicity groups,[24] the other study found the opposite.[25] We know of no studies comparing patients with unknown Hispanic ethnicity to those with known ethnicity in survival and related factors among cancer patients.

To identify factors that may be related to the poor survival in renal cancer patients with unknown ethnicity, we compared demographic, tumor and treatment characteristics of this group with the non-Hispanic and Hispanic groups. Results showed that they were more likely to be diagnosed at advanced tumor stage and to receive chemotherapy and/or radiation therapy, but less likely to receive surgery than those with known ethnicity. The lower rate of receiving surgery and higher rate of receiving chemotherapy and radiation therapy in patients with unknown ethnicity might result from their later tumor stage, which might lead to their poorer survival. However, further multivariate analysis showed that the poor survival still existed after adjustment for tumor stage and other variables, and the survival disadvantage of the group was consistently observed in subgroups of patients stratified by tumor stage, tumor grade, cancer treatments, and demographic characteristics. Thus, factors other than those investigated in the current study may also be associated with the poorer survival among renal cancer patients with unknown ethnicity. For example, comorbid conditions, for which data were not complete and thus not used, might differ between patients with unknown ethnicity and those with known ethnicity and have affected all-cause death.

Information on health promotion behaviors and attitudes towards screening and treatments was also unavailable in our study, while behavioral and attitudinal patterns are important to investigate. In the breast cancer screening study by Kempe et al, compared to women with known race/ethnicity, women with missing race/ethnicity were less likely to seek primary care and visit doctors less frequently.[10] The reduced use of health care services by patients with missing race/ethnicity was attributed to less positive health promotion behaviors in these patients.[10]

Our findings that patients with unknown ethnicity were more likely to have missing information on tumor grade, tumor size, marital status, and other variables suggest that the missing information on ethnicity is not random.[9] The nonrandom missing data might result from some underlying differences between this group and other groups. For example, a higher percentage of missing data on tumor grade in patients with unknown ethnicity may imply less adequate or unavailable pathologic specimens for assessing tumor grade than those with known ethnicity.

While the understanding specific mechanisms behind the coded unknowns are not obvious, understanding the sources of information on Hispanic ethnicity may be helpful to infer possible mechanisms. The information on Hispanic ethnicity in the ACTUR is obtained from administrative and medical records which are often based on self-reported Hispanic ethnicity. Hispanic ethnicity is also defined by registrars using information on Hispanic origin stated on death certificates, birthplace, country of origin, life history and/or language spoken, patient's last name or maiden name found on a list of Hispanic names, and a combination of methods,[20] which is convoluted or cumbersome. When evidence from these sources is not available or not readily accessible, registrars code ethnicity as unknown. Thus, missing ethnicity may result from multiple causes, such as the absence of ethnicity entry in medical records, unavailable information on language or life history, or other factors. Less information in administrative and medical records might be related to less utilization of health care service by patients or less interaction between patients and health care providers. However, the cancer registry data do not contain data on health service utilization or patient-provider interaction, nor perceptual, cultural and structural factors, preventing us from assessing the effects of these factors. Moreover, due to lack of the information on facility and provider in our data, we were unable to investigate the extent of missing in relation to medical facilities and providers.

Our study was based on the military health care system and thus the results may not be directly generalizable

to other populations. Our results on unknown Hispanic ethnicity in the ACTUR, which was also associated with missing in other variables, suggest the need to improve the collection of data by reaching out for more engagement of patients, clinicians and registrars, and increasing patient-provider interactions.

References

1. Izquierdo JN, Schoenbach VJ. The potential and limitations of data from population-based state cancer registries. *Am J Public Health*. 2000;90(5):695-698.
2. Elliott MN, Fremont A, Morrison PA, Pantoja P, Lurie N. A new method for estimating race/ethnicity and associated disparities where administrative records lack self-reported race/ethnicity. *Health Serv Res*. 2008;43(5 Pt 1):1722-1736.
3. Long JA, Bamba MI, Ling B, Shea JA. Missing race/ethnicity data in Veterans Health Administration based disparities research: a systematic review. *J Health Care Poor Underserved*. 2006;17(1):128-140.
4. Sterne JA, White IR, Carlin JB, et al. Multiple imputation for missing data in epidemiological and clinical research: potential and pitfalls. *BMJ*. 2009;338:b2393.
5. Fiscella K, Fremont AM. Use of geocoding and surname analysis to estimate race and ethnicity. *Health Serv Res*. 2006;41(4 Pt 1):1482-1500.
6. Derose SF, Contreras R, Coleman KJ, Koebnick C, Jacobsen SJ. Race and ethnicity data quality and imputation using U.S. Census data in an integrated health system: the Kaiser Permanente Southern California experience. *Med Care Res Rev*. 2013;70(3):330-345.
7. Ryan R, Vernon S, Lawrence G, Wilson S. Use of name recognition software, census data and multiple imputation to predict missing data on ethnicity: application to cancer registry records. *BMC Med Inform Decis Mak*. 2012;12:3.
8. He Y, Yucel R, Zaslavsky AM. Misreporting, missing data, and multiple imputation: improving accuracy of cancer registry databases. *Chance (N Y)*. 2008;21(3):55-58.
9. Egleston BL, Wong YN. Sensitivity analysis to investigate the impact of a missing covariate on survival analyses using cancer registry data. *Stat Med*. 2009;28(10):1498-1511.
10. Kempe KL, Larson RS, Shetterley S, Wilkinson A. Breast cancer screening in an insured population: whom are we missing? *Perm J. Winter*. 2013;17(1):38-44.
11. Last J. *A Dictionary of Epidemiology*. New York, NY: Oxford University Press; 1995.
12. Lin SS, Kelsey JL. Use of race and ethnicity in epidemiologic research: concepts, methodological issues, and suggestions for research. *Epidemiol Rev*. 2000;22(2):187-202.
13. Ahdieh L, Hahn RA. Use of the terms 'race', 'ethnicity', and 'national origins': a review of articles in the American Journal of Public Health, 1980-1989. *Ethn Health*. 1996;1(1):95-98.
14. Grieco EM, Cassidy RC. *Overview of Race and Hispanic Origin: Census 2000 Brief*. Washington, DC: US Census Bureau; 2001. **http://www.census.gov/prod/2001pubs/c2kbr01-1.pdf**. Accessed March 5, 2014.
15. Humes KR, Jones NA, Ramirez RR. *Overview of Race and Hispanic Origin*: *2010*. Washington, DC: US Census Bureau; 2011. **http://www.census.gov/prod/cen2010/briefs/c2010br-02.pdf**. Accessed March 5, 2014.
16. Ennis SR, Rios-Vargas M, Albert NG. *The Hispanic Population: 2010*. Washington, DC: US Census Bureau; 2011. **http://www.census.gov/prod/cen2010/briefs/c2010br-04.pdf**. Accessed March 5, 2014.
17. Kagawa-Singer M, Dadia AV, Yu MC, Surbone A. Cancer, culture, and health disparities: time to chart a new course? *CA Cancer J Clin*. 2010;60(1):12-39.
18. Cannon AJ. Delivering culturally competent care in clinical practice: a call to action. *J Natl Med Assoc*. 2012;104(1-2):104-107.
19. Zheng L, Enewold L, Zahm SH, et al. Lung cancer survival among black and white patients in an equal access health system. *Cancer Epidemiol Biomarkers Prev*. 2012;21(10):1841-1847.
20. Tryon J. *User's Guide For ACTUR Cancer Registry Software System Abstracting Module*. Washington, DC: US Department of Defense; 2007.
21. Chow WH, Shuch B, Linehan WM, Devesa SS. Racial disparity in renal cell carcinoma patient survival according to demographic and clinical characteristics. *Cancer*. 2013;119(2):388-394.
22. Patard JJ, Leray E, Rioux-Leclercq N, et al. Prognostic value of histologic subtypes in renal cell carcinoma: a multicenter experience. *J Clin Oncol*. 2005;23(12):2763-2771.
23. Fritz A, Percy C, Lack A, et al. *International Classification of Diseases for Oncology*. 3rd ed. Geneva, Switzerland: World Health Organization; 2000.
24. Downing A, West RM, Gilthorpe MS, Lawrence G, Forman D. Using routinely collected health data to investigate the association between ethnicity and breast cancer incidence and survival: what is the impact of missing data and multiple ethnicities? *Ethn Health*. 2011;16(3):201-212.
25. Jack RH, Davies EA, Moller H. Breast cancer incidence, stage, treatment and survival in ethnic groups in South East England. *Br J Cancer*. 2009;100(3):545-550.

How the Wisconsin Cancer Reporting System's Data Quality Task Force Started a Cancer Information Management Education Program to Improve Certified Tumor Registrar Recruitment in Wisconsin

Mary Foote, MS[a]

Background

The role of the cancer registrar is essential in the effort to gather essential information on most types of cancer diagnosed or treated within a health care institution or within a defined population. These data are used to inform a variety of public health decisions and provide information for cancer diagnosis, treatment, and prevention programs. Effective January 1, 2015, all abstraction of medical records for cancer cases at Commission on Cancer (CoC)-accredited facilities must be performed by cancer registrars who have achieved the Certified Tumor Registrar (CTR) credential.

There is a national shortage of CTRs; the National Cancer Registrars Association (NCRA) registration directory, accessed in January 2013, listed just 70 CTRs for Wisconsin. Based on the average annual number of over 29,000 invasive, consolidated cancer cases in Wisconsin (diagnosed in 2006–2010), the average number of cases per CTR was 415, while the US average was 328 cases per CTR. Using this workload estimate, in comparison with other states,[1] Wisconsin was burdened with the sixth highest caseload per CTR in the United States and the highest in the Midwest. Further, there were only 6 Wisconsin candidates for the NCRA CTR-certification exam in 2013.[2]

Wisconsin Cancer Reporting System Data Quality Review

Wisconsin Cancer Reporting System (WCRS) staff analyzed data from 2010–2012 at the facility and abstractor level to identify cases reported by CTRs in CoC-approved facilities, CTRs in non-CoC facilities, and non-CTR abstractors (medical coders, clerical staff, nurses, and some physicians). The results confirmed that overall error rates varied depending on the CTR status and facility accreditation. CTRs at CoC-accredited hospitals had error rates that ranged from 0%–52% of cases per submission, with an average error rate of 2.5% per submission. CTRs at non–COC-accredited facilities had an error rate range of 0%–75% of cases per submission, with an average error rate of 4.6% per submission. Non-CTRs from all types of facilities had an error rate range of 0%–100% of cases per submission, with an average error rate of 26.2% per submission.

In many rural Wisconsin counties, smaller facilities do not usually employ CTRs and have a higher percent of unstaged cases than the state average. Final data for 2007–2011 diagnoses from 15 (of 72) small counties included over 10% (range, 10%–36%) of cases reported with unknown stage at diagnosis, relative to the state average of less than 5% reported as unknown.

WCRS Data Quality Task Force and First Steps

WCRS introduced the major objective of providing more educational resources for addressing the shortage of CTRs in Wisconsin to the Data Quality Task Force in the fall of 2012. The 2-year task force was composed of 17 members, with physicians, CTRs, researchers, and representatives from the Midwest Division of the American Cancer Society, Wisconsin Hospital Association, Rural Wisconsin Health Cooperative and universities (co-chairs were from the University of Wisconsin Carbone Cancer Center and the Medical College of Wisconsin). Members also represented large cancer care facilities such as Marshfield Clinic, Aurora Health Care, and Gundersen-Lutheran, among others. The task force concluded that the small number of education programs (only 4 NCRA–accredited associate degree programs) for the cancer registry profession and the shortage of CTRs limited the ability of the Wisconsin institutions to report their data with the required accuracy and timeliness.

The task force CTR work group explored several avenues in the fall of 2013, including a potential collaboration with the Wisconsin Workforce Development Board, Wisconsin Workforce Development's Fast Forward Program, and discussions with a technical college in central Wisconsin (an earlier attempt to start a CTR program on that college campus had failed). The available funding for workforce development in Wisconsin indicated the potential for a new education program, if we could make strategic contacts—and meet the challenge of getting the decision makers at the table. The task force coordinator interviewed staff from other state cancer registries that had not been successful in creating or maintaining CTR training education programs, to determine "lessons learned." Primary obstacles mentioned were limited general funding, insufficient enrollment, and lack of broad stakeholder support.

[a]Wisconsin Cancer Reporting System, Office of Health Informatics, Division of Public Health, Department of Health Services, Madison, Wisconsin.

Address correspondence to Mary Foote, MS. Email: mary.foote@dhs.wi.gov.

Workforce and Education Contacts

The Task Force Coordinator contacted the Director of the Department of Health Services (DHS) Workforce Development Program in September 2013 and provided a background briefing paper and talking points about the CTR professional landscape. The Director was encouraging and referred the coordinator to the health occupation education director at Wisconsin Technical College System (WTCS). That WTCS director met with the director of the DHS Workforce Development Program, task force coordinator, and co-chair in November 2014, and quickly grasped the potential for workforce development from a statewide education program. She recommended contacting the dean of health education and public safety at Southwest Wisconsin Technical College (SWTC). It was apparent at the third meeting (with task force co-chair, coordinator, and a CTR member knowledgeable about NCRA-accredited associate degree programs) in late November that the SWTC dean was confident about developing a new online cancer information management program. All 3 meetings were supported with advance briefing papers and clear talking points, and the last meeting, with examples of NCRA-accredited education curriculum. The relative lack of knowledge regarding cancer registrars was anticipated and addressed at each meeting with leaders from education and workforce fields.

The briefing papers were also condensed for press releases/announcements from 4 fundamental talking points:

1. Definition/description of CTR profession, to promote a profession that is not highly visible or understood
2. Current shortage versus demand, to emphasize the growing demand, economy, and workforce in upward recovery
3. Education pathways, to explain there are different paths per NCRA requirements
4. Salary/ job opportunities, to highlight the professional level salary and expanding job market

SWTC created the first-year curriculum, working with the task force CTR members, one with extensive knowledge of the NCRA accreditation requirements, and other state CTRs in the Wisconsin Cancer Registrars Association. The concept was first approved by the SWTC board and then by the state education board, and a proposal for funding was approved to support curriculum for an associate degree in cancer information management (CIM). The funding for program development came from a general purpose revenue grant allocated for new education programs, submitted through the Wisconsin Technical College System. The online CIM program will be seeking NCRA accreditation; there is an advisory board of CTRs (NCRA members) to guide development of curriculum required for NCRA accreditation. The program went live on the SWTC website on June 10, 2014; the site provides an overview, curriculum, administrative and program requirements, outcomes and career opportunities. Financial aid is available for this program. Details on the program are available at **https://www.swtc.edu/academics/programs/health-occupations/cancer-information-management**.

SWTC and the Data Quality Task Force members are committed to promoting the online program across the state, identifying specific methods to encourage future graduates to remain in Wisconsin after obtaining their CTR certification, and encouraging Wisconsin reporting facilities to hire new CTRs from this program.

National Cancer Registrar Association Resources

The task force benefitted greatly from NCRA resources. One CTR Task Force member represented the Wisconsin Cancer Registrars Association and also served as the NCRA Education Foundation vice chair; her familiarity with resources was instrumental in making preliminary curriculum recommendations and providing resources for future education program development.

The NCRA was awarded a 5-year cooperative agreement from the National Program of Cancer Registries to launch innovative efforts to enhance cancer surveillance data collection and use. Key components of the program include high-quality, cost-effective training; recruitment and retention initiatives; and marketing and communications programs to increase awareness of the profession and the role cancer data collection plays in benefitting public health. A positive indicator in 2013 was that 495 candidates in the United States took the CTR exam—a 33% increase from 2012.[3] The task force made extensive use of NCRA promotional materials newly available from the Careers/Workforce Development Web page dedicated to cancer surveillance workforce recruitment and retention resources (**http://www.ncra-usa.org/i4a/pages/index.cfm?pageid=3932**).

Assessment of Benefit

The public health benefit of the newly developed CIM Program for the foreseeable future will depend on the success of new student recruitment and retention, initially in 3 to 5 years (postgraduation and CTR exam). Because of the fast-track process in starting the program, there was limited time for student recruitment; 4 students were enrolled for the first semester. The grant awarded to SWTC for the CIM program provided funds for marketing the new education program. In the spring of 2015, SWTC held a successful open house to promote the CIM program and attracted 40 potential students. The SWTC Network Specialist also visited hospitals and facilities with CIM-specific brochures to promote the program. The marketing campaign emphasized the positive features of the CTR profession: job security, good benefits, professional salary, and potential for a variety of career choices and advancement. The number of enrollees for the fall 2015 semester has increased to 19 students, surpassing the planned capacity of 15, because some are part time.[4]

It is hoped the number of CTRs in Wisconsin will increase, resulting in more accurate and timely data for WCRS and ultimately for cancer surveillance and research.

Promotion of CIM Program

WCRS, along with the Wisconsin Cancer Council (membership of over 100 organizations) and other

stakeholders will continue to support and promote the new CIM education program and monitor program enrollment and certification of CTRs. Updates about promoting the Cancer Information Management Program from the final Data Quality Task Force meeting December 17, 2014 included the following:

- The CIM program was added to the Wisconsin Tech College Guidebook as of October 2014.
- Data Quality Task Force members agreed there needs to be more awareness of the cancer registrar profession. Cancer-related groups continue to promote the CTR profession, and present features in newsletters and the media.
- The Director of Wisconsin Technical College System meets with Wisconsin Hospital Association staff on Governor's Task Force and will raise the issue of creating and marketing jobs for future grads.
- Data Quality Task Force members posted the link to the CIM program website.
- Information about the CIM program was posted on secondary education websites in Wisconsin.

Employment opportunities for CIM graduates are excellent. The changing needs of health care facilities and current cancer reporting requirements will recommend this as a viable, sustainable career in our mix. Additionally, we plan on a future certificate option per NRCA guidelines.

——Katie Garrity, Dean of Health Education and Public Safety, Southwest Wisconsin Technical College

Acknowledgments

Special thanks go to Data Quality Task Force CTR work group: Sara Beise, RHIT, CTR, Cancer Registry Coordinator, St. Vincent Hospital; Amy Williamson, Task Force Co-Chair, MPP, UW Carbone Cancer Center and Kathy Farnsworth, Public Policy Coordinator, Wisconsin Comprehensive Cancer Control Program. Indispensable endorsements came from Nancy Freeman, Executive Director of the Wisconsin Cancer Council, and Dr. Frank Wilson, Task Force Co-Chair, Medical College of Wisconsin. Laura Stephenson, Quality Assurance Specialist at WCRS, provided data quality assessments. We are most grateful for the education expertise of Kathy Loppnow, Director of Wisconsin Technical College System and Katie Garrity, Dean of Health Programs, Southwest Wisconsin Technical College, who were responsible for fast-tracking the necessary approvals and grant application in record time for the opening of the CIM program in the fall of 2014. Thanks to all task force members who approved Letters of Support, promoted the new CIM program, and offered enthusiastic support.

References

1. Copeland G, Lake A, Firth R, Wohler B, Wu XC, Schymura M, Hofferkamp J, Sherman R, Kohler B, eds. *Cancer in North America: 2008-2012. Volume Two: Registry-specific Cancer Incidence in the United States and Canada*. Springfield, IL: North American Association of Central Cancer Registries; 2015.
2. National Cancer Registrars Association. Council on Certification. 2012 and 2013 CTR Exam Results.
3. National Cancer Registrars Association. *Salary Considerations for Cancer Registrars: Updated 2012 Survey Data*. Alexandria, VA: National Cancer Registrars Association; 2013.
4. National Cancer Registrars Association. *NCRA Workload and Staffing Study. Guidelines for Hospital Cancer Registry Programs*. Alexandria, VA: National Cancer Registrars Association; 2011.
5. National Cancer Registrars Association, National Program of Cancer Registries. *NCRA/NPCR Workload and Time Management Study. Guidelines for Central Cancer Registry Programs*. Alexandria, VA: National Cancer Registrars Association; 2013.
6. NRCA-accredited education programs. National Cancer Registrars Association website. **http://www.ncra-usa.org/i4a/pages/index.cfm?pageid=3914**. Accessed June 18, 2015.

The Good, the Bad, the Ugly…and the Even Better of Rapid Abstracting

Karen Coyne, RN, CTR, MSc[a]

Introduction

With the ever increasing and welcome demand for our cancer registry data at Moffitt Cancer Center (an National Cancer Institute–designated Comprehensive Cancer Center), the traditional cancer registry model of abstracting 4 to 6 months after date of first contact became more and more of a hindrance to the mutual goals and vision for use of our data. We set a goal of utilizing the American College of Surgeon's Rapid Quality Reporting System and we knew that, to use the functionality of that system to improve patient timelines for treatment, we would need to rapidly abstract all our analytic breast and colorectal cases. Rapid abstracting is the method whereby all diagnostic, surgical, and staging information must be gathered in order to complete the first half of the abstract 4 to 6 weeks from date of first contact. Neoadjuvant therapy data can also be collected at this point. The second phase of the abstract completion takes place 4 months from date of diagnosis. Surgery-only cases (eg, early-stage melanoma) would be completed immediately. With very limited resources and our vision in mind, we were determined to achieve this and had a number of brainstorming sessions to bring this vision to a reality. At the same time, we had become more a "passive follow-up registry," meaning that we were now obtaining electronic vital statistics from both the Social Security Death Index (SSDI) and our state cancer registry. The older manual method of sending letters to physician offices and patients was becoming outmoded and less frequent. Having a small team of follow-up personnel that we could repurpose to help us with our rapid abstracting became the cornerstone of rapid abstracting for all our cases. At Moffitt, we accession 11,000 cases annually; two-thirds of our cases are analytic cases.

Methods

The first thing we did was to write a convincing and focused business plan outlining the advantages to the hospital if we were funded to switch to rapid abstracting:

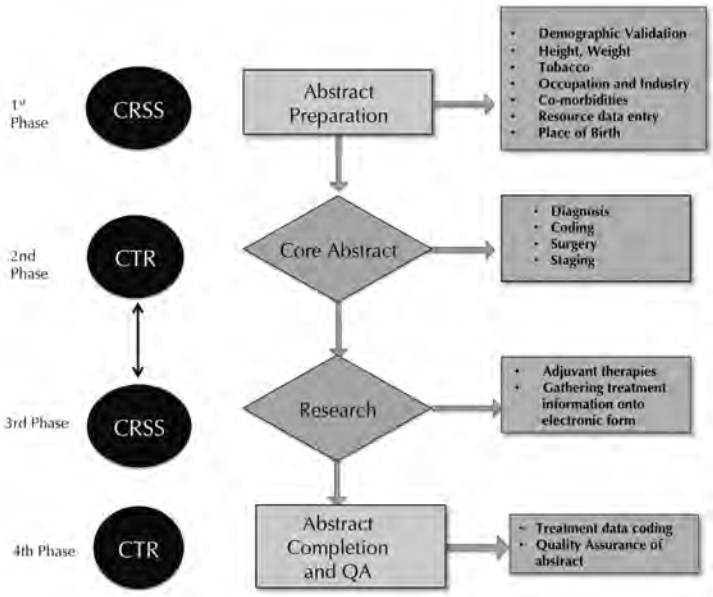
- We could get caught up with our state reporting
- The Rapid Quality Reporting System would be utilized
- Real time data would be provided

Hospital administrators do not always see how cancer registry data can be used to its best advantage; therefore, we provided clear, concise examples using pie charts, bar graphs, and line graphs. We wanted to show how real-time data could effectively be used to serve as the data cornerstone for research and clinical goals.

We rewrote the job descriptions of the members of our follow-up team, describing how their skills and education could be utilized to assist us with abstracting. We broke the abstract down into 4 distinct phases (Figure 1):

- Phase 1: Preparation of the abstract
- Phase 2: Diagnostic and surgical coding as well as staging
- Phase 3: Treatment research (gathering treatment information)
- Phase 4: Treatment coding and quality assurance of the abstract

Figure 1. 4 Abstract Phases



Our approach was to have a cancer registry support specialist (CRSS, previously our follow-up team) prepare the abstract by validating the demographics and collecting some basic preexisting and contributory factors such as tobacco use. The CRSS then flagged the case in the system to alert the certified tumor registrar (CTR) that the case was ready for Phase 2. The CTR abstracted the case up to the point when the surgical pathology report was ready, then sent the case back to the CRSS team indicating the treatment that the patient would most likely have, according to the National Comprehensive Cancer Network guidelines for that cancer site and stage at diagnosis. Phase 3 was then carried out by the CRSS, who sought the treatment

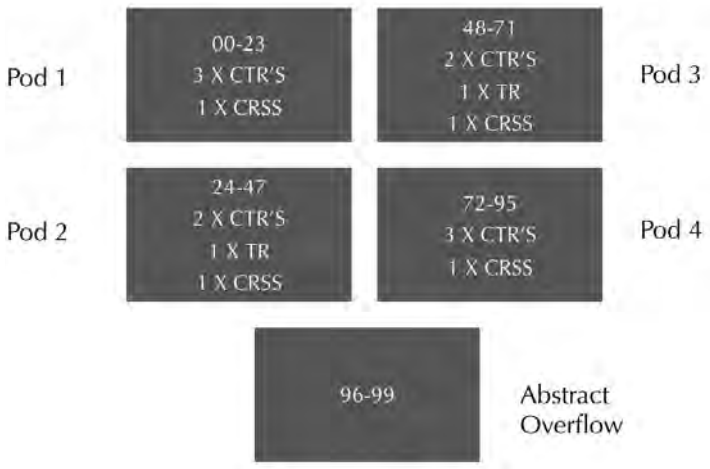
[a]Moffitt Cancer Center, Tampa, Florida.

Address correspondence to Karen Coyne, RN, CTR, Msc. Email: Karen.coyne@moffitt.org.

information, including contacting outside physician offices and other hospitals if necessary. The case was then bounced back to the CTR to code and complete the treatment information. Phases 1 and 2 took place within 4 to 6 weeks from date of first contact. Phase 3 took place 2 to 4 months after date of first contact and the entire abstract was completed once the patient had received all their treatment. The number of times the abstract went back and forth between the CTR and CRSS was unlimited, as patients received their various treatment modalities. With the use of user-defined fields in our registry software, we created "flags" and to-do lists for both teams to allow the cases to flow back and forth seamlessly.

With such a large registry, we quickly realized that the high caseload was more manageable by breaking the teams into subgroups which we termed *pods*. We created 5 distinct pods (working groups): 4 abstracting pods and 1 casefinding pod. Within each pod, we had 2 CTRs: 1 trainee CTR and 1 CRSS. We assigned team members based on experience and skill mix, as well as ensuring different personality types within a pod. We needed a team member with strong leadership skills as well as a person with lots of abstracting experience to educate and advise our trainee abstractors. Each pod was divided by medical record numbers and also each abstractor had their own number range so that the same abstractor got their own abstracts back to code and complete (Figure 2). This was important for staff satisfaction, cohesiveness, and quality assurance of the abstract. At the beginning of our transition, we had team building ("pod building") sessions, including an afternoon at the bowling alley, to help our pods work together as a team. This was not only fun but served to bring us closer together to achieve our mutual goals.

Figure 2. Number Ranges for Pods



Results

Our business plan outlined a goal to achieve rapid abstracting within 2 years. We planned to move slowly toward our goal by setting ourselves bite-sized goals of abstracting 5 weeks' worth of cases within each month. That way, our progress would be slow but sure, and we would move steadily to catch up and reach all-site rapid abstracting. We did not envision that our system would work as well as it did, as it was theoretically feasible, but had yet to be proven. We were ecstatic when we reached rapid abstracting at 15 months instead of the anticipated 24 months. Having the help of the CRSSs who support the abstracting process freed up time for the CTRs to focus on coding and staging as well as the highly important quality assurance of the abstracts. Another benefit to our system is that our support specialists are now the next in line for becoming trainee abstractors. We have created a career pathway for new and enthusiastic employees who strive to become certified. By starting off as a CRSS, then moving into a trainee abstractor position, becoming certified is a reachable goal. Our registry also wins by having high quality abstractors.

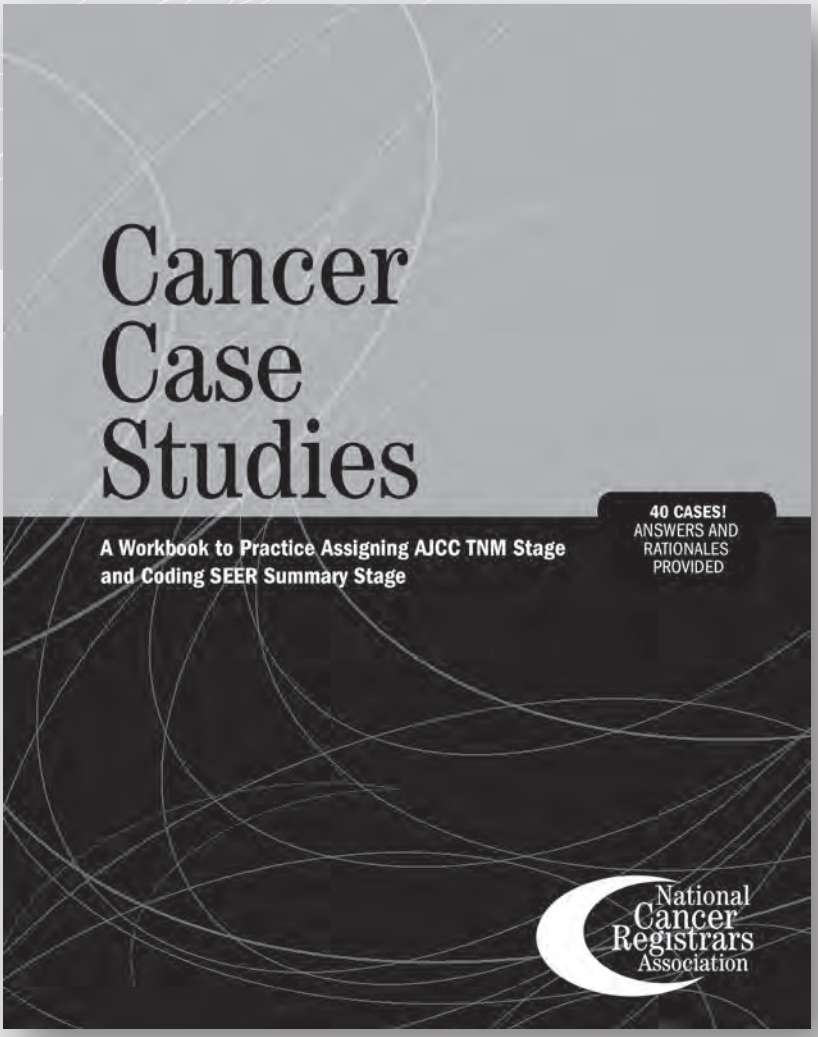
Discussion

Rapid abstracting cannot be achieved until casefinding is first caught up. We knew we could not abstract 4 to 6 weeks after date of first contact if casefinding was behind. We focused on getting caught up and having enough cases in suspense to begin our plan. One of our main issues is the ongoing class 30 cases. Some patients come to Moffitt for part of their staging workup and then return (or not) for treatment with us. It is very difficult to know if they will be analytic or a class 30 at the outset. For these undetermined cases, we wait to see if they return and try to assign class 30 only when they are true class 30 patients. This originally was trial and error and, indeed, we inadvertently abstracted some cases as nonanalytic and had to go back and reabstract and resubmit to the state cancer registry.

Communication between our CTRs and CRSS team members is crucial. We now have daily podcasts—15-minute brief huddles (conference calls, as most of our teams are remote) in which the teams touch base and discuss cases, including abstracting conundrums and also the important water-cooler or coffee-pot chat that shows we are human beings with a life outside of work. Having their own abstracts returned to them to complete really helps our abstractors. There was dissatisfaction with completing someone else's abstract, and, as our abstractors are proud of their work, they do prefer to complete and perform quality assurance on their own abstracts. This final once-over is separate from our registry's formal quality assurance process, but does serve to provide higher quality data.

Conclusion

Rapid abstracting is achievable by thinking outside the box (an old cliché, but a good one). When we had a vision and very little resources, we didn't give up and were determined to make it work with what we had. What we have is a unique and creative way of working with a team of enthusiastic dreamers who jumped at the chance to take our registry to a higher level and a new century. I have termed this article *How We Do It* because we do this as an entire team with every team member contributing and making a difference.



Get Ready for the Transition!

NCRA's Latest Publication Provides Registrars the Opportunity to Practice Assigning AJCC TNM Stage and Coding SEER Summary Stage.

Go to **www.ncra-usa.org/casestudies** to order!

Setting Expectations

Michele Webb, CTR

In May 2011, Sainsbury's, a grocery store chain in the United Kingdom, received a letter from a little girl named Lily. "Why is tiger bread called tiger bread?" she asked, referring to one of the store's bakery items. "It should be called giraffe bread. Love, Lily Robinson age 3 and ½." Chris King, a customer service manager, looked at the product and agreed with Lily. The pattern on the bread *did* resemble a giraffe more than a tiger. To everyone's surprise, he responded to Lily and said, "I think renaming tiger bread giraffe bread is a brilliant idea—it looks much more like blotches on a giraffe than the stripes on a tiger, doesn't it? It is called tiger bread because the first baker who made it a looong time ago thought it looked stripy like a tiger. Maybe they were a bit silly." He signed the letter "Chris King (age 27 & 1/3)" and enclosed a gift card. On January 31, 2012 the company announced that they were renaming the bread giraffe bread.[1]

Can't you just picture little Lily Robinson's face when she went to the grocery store with her mum and pulled a package of giraffe bread off the shelf? What a shining example of customer service that undoubtedly resulted in increased sales and many new satisfied customers.

Each of us wants to receive excellent customer service, whether we are standing in line for a coffee, putting tires on our cars, going shopping at the mall, or even a patient in a hospital.

But, before we can discuss how to deliver customer service, we need to fully understand what a customer is. So, let us turn to the Oxford Dictionary. The secondary definition of the word customer is, "A person or thing of a specified kind that one has to deal with...."[2]

Based on this definition, cancer registrars can easily identify their customers to include any physician, administrator, nurse, or staff person we encounter each day. But, let's look a bit deeper. The definition states "a person or thing of a specified kind." Based on this broader statement, it seems reasonable to also include the patients and providers who share the data with us directly or indirectly.

In 2011, Harris Research published in the *Oracle Customer Experience Impact Report* that 86% of US consumers would pay more for a better service experience and 89% would completely stop doing business with a company if they experienced poor customer service. Later, in the *2012 Global Customer Service Barometer,* it was reported that only 7% of US consumers felt that their customer service experiences exceeded their typical expectations.[3]

If the responses in these studies are typical of customer service across the board in all industries and work environments, then cancer registrars should sit up and take notice. Do you know what your customers are saying about the service you and your colleagues deliver? Are you making a favorable impression that is backed up by strong performance?

In the week prior to writing this article, I had received news from 2 colleagues who work in different organizations as cancer program administrators regarding recent interactions with their cancer registrar. In each situation, the registrar had been observed as failing to deliver basic customer service and common courtesy, resulting in a negative impact on the quality of care or a new business venture in each of the 2 hospitals. The individuals writing to me were understandably concerned and frustrated with their experience. It was disheartening and painful to listen to their stories.

Please understand that I am not implying that all registrars provide poor customer service, nor am I seeking to cast doubts on anyone's ability to collect and provide high-quality data. However, I do believe that all cancer registry professionals should conduct an honest self-assessment of their customer service to determine where improvements must be made to meet the new and changing scientific, clinical, analytical, and business needs of their health care partners.

It is not appropriate for cancer registrars to neglect the needs of their customers on the basis of busyness, changing standards, personal differences, or any other excuse. In our current environment, where budgets are stretched beyond their limits and health care costs are increasing at alarming rates, failure to deliver strong, team-centric, collaborative service will be viewed as misguided and irresponsible by the very people we are to serve. Registries who fail to deliver exceptional customer service will struggle with a number of issues that will rob them of the satisfaction and value that they were designed to provide. Is it time for a change? If so, you may be able to identify with Rick Warren who said, "If you don't like what you are reaping in life, change what you are planting."

In order to deliver favorable impressions backed by a strong performance, you can learn how to set your customer's expectations in such a way that you deliver and exceed them 100% of the time. Here is a 3-step process you can begin using right away:

1. Ask your customer what is most important to them and what would need to happen for them to be completely satisfied with your service or the volume, type, or integrity of the data you provide.
2. Determine whether your way of doing your work can accommodate their visions and needs. If it cannot, identify alternatives for at least 1 component of what the customer needs to produce the exact results they want.
3. Once you have reached mutual agreement, make the decision to immediately move forward. Meet your responsibilities 1% to 10% better, faster, and more efficiently than you promised.

By setting expectations that you consistently exceed, you will boost your customer's satisfaction with your service and create champions for the cancer registry operation. Champions of your service and data will find ways to talk about your level of service and bring you new opportunities for programmatic and professional growth based on the credibility and integrity of service.

Just like little Lily Robinson, you can ask a simple question that will revolutionize and rebrand your work, your profession, and the industry. Simple observations about what your customer needs can be used to change your mindset, culture, and the trajectory of your cancer program and patient care experience. Ultimately, there are no limits on what cancer registrars can accomplish by setting favorable impressions backed by the delivery of strong performances exceeding the needs of their customers and healthcare partners.

References

1. Tiger bread renamed giraffe bread by Sainsbury's. BBC News website. **http://www.bbc.com/news/business-16812545**. Published January 31, 2012. Accessed June 16, 2015.
2. Customer. Oxford Dictionaries website. **http://oxforddictionaries.com/us/definition/american_english/customer**. Accessed May 5, 2015.
3. Todd D. Thrill your customers. *Success Magazine*. May 2015:57-59.

Michele is a cancer registry speaker, educator, and independent contractor living in Rancho Cucamonga, California. She owns many websites including: ***www.CancerRegistrar.com***, ***www.RegistryMindset.com***, *and* ***http://MicheleWebb.com***, *offering cancer registry leadership, mentoring and continuing education opportunities. Your comments are welcomed by email to michele@michelewebb.com.*

Journal of Registry Management Continuing Education Quiz—SUMMER 2015

AVAILABILITY OF TNM STAGING DATA ELEMENTS IN THE MEDICAL RECORD AND TRAINING NEEDS ASSESSMENT: RESULTS FROM THE 2014 SEER TRAINING NEEDS ASSESSMENT FOR TNM STUDY

Quiz Instructions: The multiple choice or true/false quiz below is provided as an alternative method of earning CE credit hours. Refer to the article for the ONE best answer to each question. The questions are based solely on the content of the article. Answer the questions and send the original quiz answer sheet and fee to the NCRA Executive Office before the processing date listed on the answer sheet. Quizzes may not be retaken nor can NCRA staff respond to questions regarding answers. Allow 4–6 weeks for processing following the submission deadline to receive return notification of your completion of the CE process. The CE hour will be dated when it is submitted for grading; that date will determine the CE cycle year.

After reading this article and taking the quiz, the participants will be able to:

- Discuss the general availability of the T, N, and M elements in the medical record
- Identify specific training needs to assist registrars in TNM assignment
- Describe differences in agreement between participant and review panel responses in terms of data elements and cancer sites

1. The objectives of this study were to determine how often:

	physician-assigned staging was available	registrars were required to assign TNM	physician staging agreed with information in the medical record	registrars had to adjudicate information found in the medical record
a)	Y	Y	N	N
b)	Y	N	N	Y
c)	Y	N	Y	N
d)	N	N	Y	Y

2. In the United States, the organization leading the effort to develop a standardized staging system is:

	UICC	NCRA	AJCC	SEER
a)	N	N	N	Y
b)	N	N	Y	N
c)	N	Y	N	N
d)	N	N	N	N

3. Cases selected for this study include:
   a) only those submitted from CoC-accredited facilities
   b) only those submitted from non–CoC-accredited facilities
   c) female breast, prostate, colon, lung and ovary
   d) female breast, prostate, colon, lung and bladder

4. As part of the medical record preparation, the study authors worked to ensure that:
   a) both single- and multiple-primary records were included
   b) primary site and tumor grade combinations were valid
   c) both date of birth and Social Security number were available
   d) stage and stage-related data elements were removed

5. The element that required the most adjudication due to disagreement between reviewers was:
   a) clinical stage group
   b) clinical T
   c) pathologic stage group
   d) pathologic T

6. Of the 843 participants in this study, most:

	worked in CoC-accredited facilities	abstracted more than 500 cases annually	regularly assigned TNM stage	recently completed TNM training
a)	Y	Y	Y	N
b)	Y	Y	N	Y
c)	Y	N	Y	Y
d)	N	Y	Y	Y

7. According to Table 2, *Percentage of Medical Records that Contained Each Data Element:*
   a) colon cases were least likely to contain clinical T
   b) lung cases were most likely to contain pathologic M
   c) clinical stage group was available more often than pathologic
   d) pathologic stage group was available more often than clinical

8. According to Table 3, *Percentage of All Responses that Agreed with the Preferred Answer at the Detailed Level of TNM Staging by Cancer Site among All Participants, Those Who Reported Regularly Assigning TNM (Reg Assign), and Those Who Did Not (Not Reg Assign):*
   a) clinical N for colon had low agreement
   b) pathologic T for colon had low agreement
   c) the assignment of M had the highest agreement
   d) the assignment of SS2000 had the highest agreement

9. The strengths of this study include:
   a) limiting the cases to those that were both difficult and rare
   b) limiting the cases to those that were physician-staged
   c) using multiple cases with disagreement on the preferred answer
   d) using a large number and variety of cases

10. The results of this study suggest that more training should be directed toward registrars:
    a) with limited experience assigning TNM
    b) who regularly assign TNM
    c) regardless of their experience in assigning TNM
    d) who are newly credentialed

The *JRM* Quiz and answers are now available through NCRA's Center for Cancer Registry Education (CCRE). For your convenience, the JRM article and quiz can be accessed online at **www.CancerRegistryEducation.org/jrm-quizzes**. Download the article, complete the quiz and claim CE credit all online.

Journal of Registry Management Continuing Education Quiz **Answer Sheet**

Available online at www.cancerregistryeducation.org/jrm-quizzes

Please print clearly in black ballpoint pen.

First Name | M.I. | Last Name

Address

Address

City | State/Province | ZIP Code/Postal Code

NCRA Membership Number (MUST complete if member fee submitted) | CTR Number

Instructions: Mark your answers clearly by filling in the correct answer, like this ■ not like this ☒. Passing score of 70% entitles one (1) CE clock hour per quiz.

Please use black ballpoint pen.

1	A	B	C	D
2	A	B	C	D
3	A	B	C	D
4	A	B	C	D
5	A	B	C	D
6	A	B	C	D
7	A	B	C	D
8	A	B	C	D
9	A	B	C	D
10	A	B	C	D

Submit the original quiz answer sheet only!
No photocopies will be accepted.

For Internal Use Only

Date Received:_____

Amount Received:_____

Notification Mailed: _____

This original quiz answer sheet will not be graded, no CE credit will be awarded, and the processing fee will be forfeited unless postmarked by:

September 30, 2017

Quiz Identification Number:

4202.01

JRM Quiz Article:

AVAILABILITY OF TNM STAGING DATA ELEMENTS IN THE MEDICAL RECORD AND TRAINING NEEDS ASSESSMENT: RESULTS FROM THE 2014 SEER TRAINING NEEDS ASSESSMENT FOR TNM STUDY

☐ Processing Fee: **Member $25** **Nonmember $35**

☐ Payment is due with submission of answer sheet. Make check or money order payable to NCRA. US currency only. Do not send cash. No refund under any circumstances. Please allow 4–6 weeks following the submission deadline for processing.

Please check one:

☐ Enclosed is check #_____ (payable to NCRA)

☐ Charge to the following card:

☐ MasterCard (16 digits) ☐ Visa (13 or 16 digits) ☐ American Express

Card Number_____ Exp. Date _____

Signature _____

Print Cardholder's Name _____

Telephone # _____

Mail to: ***NCRA Executive Office***
JRM CE Quiz
1330 Braddock Place
#520
Alexandria, VA 22314

National Cancer Registrars Association
CALL FOR PAPERS

Vonetta L. Williams, PhD, MPH, CTR | EDITOR-IN-CHIEF, *JRM*

The *Journal of Registry Management*, official journal of the National Cancer Registrars Association (NCRA), announces a call for original manuscripts on registry methodology or research findings related to the 7 subjects listed below and related topics.

Topics:

1. **Birth Defects Registries**
2. **Cancer Registries**
   a. **AJCC TNM Stage**
   b. **Cancer and Socioeconomic Status**
   c. **Cancer and Health Disparities**
3. **Trauma Registries**
4. **Recruitment, Training, and Retention**
5. **Public Relations**
6. **Quality Review**
7. **Registry Management**

Contributed manuscripts are peer-reviewed prior to publication.
Manuscripts of the following types may be submitted for publication:

1. **Methodology Articles** addressing topics of broad interest and appeal to the readership, including methodological aspects of registry organization and operation.
2. **Research articles** reporting findings of original, reviewed, data-based research.
3. **Primers** providing basic and comprehensive tutorials on relevant subjects.
4. **"How I Do It" Articles** describe tips, techniques, or procedures for an aspect of registry operations that the author does particularly well. The "How I Do It" feature in the Journal provides registrars with an informal forum for sharing strategies with colleagues in all types of registries.
5. **Opinion papers/editorials** including position papers, commentaries, essays, and interviews that analyze current or controversial issues and provide creative, reflective treatments of topics related to registry management.
6. **Bibliographies** which are specifically targeted and of significant interest will be considered.
7. **Letters to the Editor** are also invited.

Address all manuscripts to: Vonetta L. Williams, PhD, MPH, CTR, Editor-in-Chief, *Journal of Registry Management*, (813) 745-1783, JRMEditor@ncra-usa.org.

Manuscript submission requirements are given in "Information for Authors" found on the inside back cover of each *Journal* and on the NCRA Web site at **http://www.ncra-usa.org/jrm**.

INFORMATION FOR AUTHORS

Journal of Registry Management (JRM), the official journal of the National Cancer Registrars Association, invites submission of original manuscripts on topics related to management of disease registries and the collection, management, and use of cancer, trauma, AIDS, and other disease registry data. Reprinting of previously published material will be considered for publication only when it is of special and immediate interest to the readership. *JRM* encourages authorship by Certified Tumor Registrars (CTRs); special value is placed on manuscripts with CTR collaboration and publication of articles or texts related to the registry profession. CTR continuing education (CE) credits are awarded; a published chapter or full textbook article equals 5 CE hours. Other published articles or documents equal CE hours. All correspondence and manuscripts should be addressed to the Vonetta L. Williams, PhD, MPH, CTR, Editor-in-Chief at JRMEditor@ncra-usa.org or (813) 745-1783.

Manuscripts may be submitted for publication in the following categories: **Articles** addressing topics of broad interest and appeal to the readership, including **Methodology papers** about registry organization and operation; **Research papers** reporting findings of original, reviewed, data-based research; **Primers** providing tutorials on relevant subjects; and **"How I Do It"** papers are also solicited. **Opinion papers/editorials** including position papers, commentaries, and essays that analyze current or controversial issues and provide creative, reflective treatments of topics related to registry management; **Letters to the Editor**; and specifically-targeted **Bibliographies** of significant interest are invited.

The following guidelines are provided to assist prospective authors in preparing manuscripts for the *Journal*, and to facilitate technical processing of submissions. Failure to follow the guidelines may delay consideration of your manuscript. Authors who are unfamiliar with preparation and submission of manuscripts for publication are encouraged to contact the Editor for clarification or additional assistance.

Submission Requirements

Manuscripts. The terms manuscripts, articles, and papers are used synonymously herein. Email only submission of manuscripts is encouraged. If not feasible, submit the original manuscript and 4 copies to the Editor. Manuscripts should be double-spaced on white 8-1/2" x 11" paper, with margins of at least 1 inch. Use only letter-quality printers; poor quality copies will not be considered. Number the manuscript pages consecutively with the (first) title page as page one, followed by the abstract, text, references, and visuals. The accompanying cover letter should include the name, mailing address, email address, and telephone number of the corresponding author. For electronic submission, files should be IBM-compatible format in Corel WordPerfect™, Microsoft® Word for Windows®, or converted to ASCII code.

Manuscripts (Research Articles). Articles should follow the standard format for research reporting (Introduction, Methods, Results, Discussion, References), and the submission instructions outlined above. The introduction will normally include background information, and a rationale/justification as to why the subject matter is of interest. The discussion often includes a conclusion subsection. Comprehensive references are encouraged, as are an appropriate combination of tables and figures (graphs).

Manuscripts (Methodology/Process Papers). Methodology papers should follow the standard format for research reporting (Introduction, Methods, Results, Discussion), or for explanatory papers not reporting results (Introduction, Methods, Discussion), as well as the submission instructions outlined above.

Manuscripts ("How I Do It" articles). The *"How I Do It"* feature in the *Journal* provides registrars with a forum for sharing strategies with colleagues in all types of registries. These articles describe tips, techniques, or procedures for an aspect of registry operations that the author does particularly well. When shared, these innovations can help registry professionals improve their skills, enhance registry operations, or increase efficiency.

"How I Do It" articles should be 1,500 words or less (excepting references) and can contain up to 2 tables or figures. To the extent possible, the standard headings (Introduction, Methods, Results, Discussion) should be used. If results are not presented, that section may be omitted. Authors should describe the problem or issue, their solution, advantages (and disadvantages) to the suggested approach, and their conclusion. All submitted *"How I Do It"* articles will have the benefit of peer/editorial review.

Authors. Each author's name, degrees, certifications, title, professional affiliation, and email address must be noted on the title page exactly as it is to appear in publication. The corresponding author should be noted, with mailing address included. Joint authors should be listed in the order of their contribution to the work. Generally, a maximum of 6 authors for each article will be listed.

Title. Authors are urged to choose a title that accurately and concisely describes the content of the manuscript. Every effort will be made to use the title as submitted; however, *Journal of Registry Management* reserves the right to select a title that is consistent with editorial and production requirements.

Abstract. A brief abstract must accompany each article or research paper. The abstract should summarize the main point(s) and quickly give the reader an understanding of the manuscript's content. It should be placed on a page by itself, immediately following the title page.

Length. Authors are invited to contact the Editor regarding submission of markedly longer manuscripts.

Style. Prepare manuscripts using the *American Medical Association Manual of Style,* 10th ed. (2007).

Visuals. Use visuals selectively to supplement the text. Visual elements—charts, graphs, tables, diagrams, and figures—will be reproduced exactly as received. Copies must be clear and properly identified, and preferably emailed. Each visual must have a brief, self-explanatory title. Submit each visual on a separately numbered page at the end of the manuscript, following the references.

Attribution. Authors are to provide appropriate acknowledgment of products, activities, and support especially for those articles based on, or utilizing, registry data (including acknowledgment of hospital and central registrars). Appropriate attribution is also to be provided to acknowledge federal funding sources of registries from which the data are obtained.

Reerences. References should be carefully selected, and relevant. References must be numbered in order of their appearance in the text. At the end of the manuscript, list the references as they are cited; do not list references alphabetically. Journal citations should include author, title, journal, year, volume, issue, and pages. Book citations should include author, title, city, publisher, year, and pages. *Authors are responsible for the accuracy of all references.* Examples:

1. LeMaster PL, Connell CM. Health education interventions among Native Americans: a review and analysis. *Health Education Quarterly.* 1995;21(4):521-538.

2. Hanks GE, Myers CE, Scardino PT. Cancer of the prostate. In: DeVita VT, Hellman S, Rosenberg SA. *Cancer: Principles and Practice of Oncology*. 4th ed. Philadelphia, PA: J.B. Lippincott Co.; 1993:1073–1113.

Key words. Authors are requested to provide up to 5, alphabetized key words or phrases which will be used in compiling the Annual Subject Index.

Affirmations

Copyright. Authors submitting a manuscript do so on the understanding that if it is accepted for publication, copyright in the article, including the right to reproduce the article in all forms and media, shall be assigned exclusively to NCRA. NCRA will not refuse any reasonable requests by the author(s) for permission to reproduce any of his or her contributions to the *Journal.* Further, the manuscript's accompanying cover letter, signed by all authors, must include the following statement: "We, the undersigned, transfer to the National Cancer Registrars Association, the copyright for this manuscript in the event that it is published in *Journal of Registry Management.*" Failure to provide the statement will delay consideration of the manuscript. It is the author's responsibility to obtain necessary permission when using material (including graphs, charts, pictures, etc) that has appeared in other published works.

Originality. Articles are reviewed for publication assuming that they have not been accepted or published previously and are not under simultaneous consideration for publication elsewhere. If the article has been previously published or significantly distributed, this should be noted in the submission for consideration.

Editing

Journal of Registry Management reserves the right to edit all contributions for clarity and length. Minor changes (punctuation, spelling, grammar, syntax) will be made at the discretion of the editorial staff. Substantive changes will be verified with the author(s) prior to publication.

Peer Review

Contributed manuscripts are peer-reviewed prior to publication, generally by 3 reviewers. The *Journal* Editor makes the final decision regarding acceptance of manuscripts. Receipt of manuscripts will be acknowledged promptly, and corresponding authors will be advised of the status of their submission as soon as possible.

Reprints

Authors receive 5 complimentary copies of the *Journal* in which their manuscript appears. Additional copies of reprints may be purchased from the NCRA Executive Office.

Journal of Registry Management

NCRA Executive Office
1330 Braddock Place
#520
Alexandria, VA 22314

PRESORTED
STANDARD
U.S. POSTAGE
PAID
DULLES, VA
PERMIT #6418

ADDRESS SERVICE REQUESTED

SUSTAINABLE FORESTRY INITIATIVE
Certified Sourcing
www.sfiprogram.org
SFI-00359

100% green power wind & solar

Printed on SFI fiber sourcing paper with non-petroleum, vegetable based inks and manufactured with renewable electricity